SUPPORT FOR FAMILIES WHOSE CHILD DIES SUDDENLY FROM ACCIDENT OR ILLNESS

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ABSTRACT

This study is concerned with the support of families after the sudden, unexpected death of their children from accident or illness. It would appear, that as such deaths are relatively uncommon today in the Western world, families may receive little or no support. The study firstly considers attitudes to bereavement over the centuries. Secondly, drawing on current research, it considers the impact of child death on family members, the manner in which family members may affect each other, and finally, how those outside the close family may hinder or help. The methodological issues of bereavement research will be discussed with specific reference to the two studies presented. Phase 1 considers parents' perceptions of support after the sudden death of their child; Phase 2 forms the major part of the thesis, where, as a result of the findings from Phase 1, an intervention to assist health visitors in helping bereaved families is assessed. The findings of Phase 1 are presented followed by a detailed account of how the intervention was devised. This is followed by a presentation of the findings from Phase 2, involving 72 bereaved parents and their health visitors. This study finds that support for bereaved families was perceived to be satisfactory by the majority of bereaved parents both from informal and formal sources. Two thirds of all their health visitors had received bereavement training in contrast to Phase 1, where only a quarter had done so. This is an encouraging finding, demonstrating the importance of how training has improved support. Although the intervention made no significant difference to the support of parents, it was found helpful and useful by the majority of the health visitors who had received it. The implications of this study for research, practice and theory are discussed.

DEDICATION AND ACKNOWLEDGEMENTS

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I dedicate this thesis to my three wonderful children, Peter, Paul and Nicola, and my three beautiful grand-children, Carragh, William and Darcy.

AUTHOR'S DECLARATION

I declare that the work in this thesis was carried out in accordance with the Regulations of the University of Bristol. The work is original except where indicated by special reference in the text and no part of the thesis has been submitted for any other degree. Any views expressed are those of the author and in no way represent those of the University of Bristol.
The thesis has not been presented to any other University for examination either in the United Kingdom or overseas.

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What we call the beginning is often the end
And to make an end is to make a beginning.
The end is where we start from.

T.S. Eliot (1942)
from "Little Gidding" in
the last of "Four Quartets"

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CHAPTER 1

INTRODUCTION

Each year around 12,000 children die from under the age of one year to nineteen years; over a half of these deaths are as a result of peri-natal death such as stillbirth and neonatal death, approximately a quarter from cot death and accidents, nearly a fifth from illness and congenital conditions, and a small percentage (2%) from socially difficult deaths such as suicide, murder, and drug abuse (OPCS, 1994).

However, the statistics do not reflect the number of people affected by such deaths. Much personal suffering, far beyond a general sense of sadness or disquiet, is likely to be experienced by close family members, parents, siblings and grand-parents. In the wider social network others, including children may be touched by the tragedy. Those who have lost a parent, a spouse and a child through death invariably describe their grief for the child as the most painful, enduring and difficult to survive (Hindmarch 1993).

The sudden death of a child is now fortunately a relatively rare occurrence in Western society, but its rarity inevitably means that when it happens, it is untimely, unprepared for, and a tremendous shock to the families (Sanders, 1989). The large number of somatic problems among bereaved parents is an indication that survivors of the death of a child are undergoing a high degree of stress (Fish, 1983; Rando, 1983; Sanders, 1980), added to which Parkes (1972), Raphael (1984) and Rando (1986) have all suggested that the sudden death and that of a child puts mourners at special risk of experiencing a more

difficult bereavement pattern. Despite these findings, it would appear that support in bereavement after the sudden death of a child is very variable. As Faulconer (1993:70) points out, there is no clear government policy on the provision of bereavement services and consequently "a patchy and variable approach" exists.

Whilst there is an expanding literature on the emotional sequelae of bereaved parents, and siblings after a sudden, unexpected death from illness or accident, there are few studies which consider the support that is offered to these families by professionals immediately after the death in hospitals or longer-term in the community. If support is offered, it is unknown as to whether bereaved parents view this as satisfactory and meeting their needs.

This thesis is guided by these two factors. It centres, in the first instance, on establishing parent's perceptions of care and how confident health care professionals and members of voluntary agencies feel about supporting such families. Secondly, drawing on these findings, it focuses on consideration of providing support within the present health care system, especially in the community. While the literature reveals that bereaved parents and bereaved siblings have often been treated separately by professionals, this study also aims to show that bereavement is a family affair where family members may influence each other and so any care that is offered, should include the whole family unit. In approaching the subject, the five guiding principles of research advocated by Stevens (1993) have been considered. These are enhancing human rationality and stripping it of its myths, achieving maximum information, striving for simplicity, seeking after valid knowledge and ensuring that the findings of research have utility.

Throughout life, loss plays an important part. Human beings constantly live with change, which in itself is loss of the familiar. One loses by leaving and being left, by changing and letting go and moving on. From early childhood, losses are an integral part of development, such experiences being part of life, being universal, unavoidable and inexorable. They are a necessary part of life which mould and change the human personality (Viorst 1988).

Whilst most people recognise and accept loss in its various forms as part of life, the loss through death of a loved one is a tragedy unequalled by any other for most bereaved people. It is an experience that occurs some time or other in nearly everyone's life, some suffering bereavement before they reach old age, when such events occur with increasing frequency. It is now recognised that separation through bereavement is one of the most disruptive and stressful of life experiences (Averill, 1968; Bowlby, 1977; Holmes & Rahe, 1967; Raphael, 1984). Whilst the death of the elderly is expected and accepted more easily, the death of a child is now relatively rare in contemporary Western society (Raphael, 1984). Consequently, few parents actively anticipate the death of their children and fortunately, few will experience such a tragedy. Rando (1986:6) has suggested that child death is "quite unlike any other loss known", and maintains that it is the form of bereavement that adults dread most, reference frequently being made to the "unjust" nature of child death and its violation of the very order of life (Dyregrov, 1990; Fulton, 1970; Rando, 1986). At any age, the loss of a child is exceedingly difficult to experience and assimilate into one's life structure (Levinson, 1978). It has been suggested that the paths parents follow as they respond to their

children's deaths can change them in some ways temporarily and in others permanently (Rubin, 1993:286).

Bowlby's (1977; 1980) classic work on attachment, separation and loss has shown that the breaking of affectional bonds has the potential to produce intense emotional distress in a variety of different forms. The relationship between parent and child is unique in terms of its physical, psychological and social significance, so that when a child dies, a profound sense of loss is likely to be experienced by the parents, not only because the child is no longer present, but because the parents may believe that they have failed in one of society's most highly esteemed roles, that of being a parent (Raphael, 1984).

When a child dies from a life-threatening illness, or as a result of still-birth or neonatal death, family members may require much support after such a tragedy. The diagnosis of childhood cancer is not the death sentence it is often presumed to be. Around 70% of children with the most common form of leukaemia have a good prognosis of long-term survival (Hindmarch, 1993). Periods of remission give rise to hope and optimism, but as successive treatments fail for those with a poor prognosis, there may be time to prepare for the inevitable outcome. Some parents will seem to cope with the dreadful knowledge; others do not or cannot even talk about the future and cope by maintaining denial to the end. In either case the question remains whether it is ever possible to feel prepared for the reality of the death when it occurs (Hindmarch, 1993). The home services provided by specialist Macmillan nurses and Malcolm Sargent social workers can help normalise a family's life and facilitate the child's death at home wherever possible.

There is now evidence to show that staff in maternity hospitals are more aware of the need for sensitive care of parents after a still-birth or neonatal death (Mander, 1994). Whilst this is to be applauded, what support is available for parents in the community is less clear.

Whilst it is recognised that much support may be required for families whose child dies expectedly from a life-threatening illness, or at birth or soon after, this thesis has concentrated on the support given to families where a child dies suddenly and unexpectedly.

Parents' reactions to the sudden, unexpected death of a child take many forms, but the overwhelming picture is of a major blow requiring great organising force in how to live life thereafter. Mirowsky (1989a) and Pearlin (1989) have suggested that events which are unscheduled, non-normative and uncontrolled are most likely to invoke distress. Such events, by upsetting the normal and expected sequence and rhythm of life, "threaten one's sense of the meaningful, predictable and secure social reality" (Mirowsky & Ross, 1989a:151). Bereaved parents robbed suddenly of their child today are surely no exception. Mulkay (1993) believes that the emotional distress of parents is so great, not only because the child's future is instantly removed but also because expectations of life after death, leading to eventual reunion, are either entirely absent, or are held with less conviction than in the past. As a result, present-day parents have no well- established patterns of social conduct and associated belief to help them through the traumatic events, which are often now centred round and processed by medical bureaucracy. The deaths of young persons in our society cause special problems, even

when a death is anticipated as a result of a life-threatening illness. Customs and attitudes of society which were appropriate in a society characterised by a high mortality rate among children and which provided support and compensation for those involved, have disappeared almost completely as the frequency of such deaths has fallen to remarkably low levels. In Western society, as the concentration of death among the elderly has become firmly established and has come to be taken for granted, so the death of the young has come to be almost unthinkable as part of the ordinary course of events (Mulkay 1993).

Whilst a range of studies has emerged investigating different aspects of the parental experience of child death (Cornwell & Nurcombe,1977; Defrain & Ernst,1978; Baumer, 1988; Friedman, 1974; Raphael, 1983), Osterweiss et al (1984) have referred to the need for more and better designed studies to expand knowledge of this category of bereavement. Most empirical research in recent years has focused on parents' emotional sequelae. Bowlby (1980/1981) examined in some detail studies that emphasised parents' anticipatory and coping responses to child death. Raphael's (1984) review of child loss considered different types of child loss from conception to adulthood. She concluded that child death commonly evoked patterns of chronic grief and irrational guilt and that the deceased child is never forgotten. Rando (1986) organised her review of child loss with a selection of specific causes of death, reflecting that child death is a multivariate event, where unique features of this type of loss deserve singular attention. At the conceptual level, a great deal of research has addressed the changes in symptomology, psychopathology and self perception in much the same way as other classes of traumatic stress (Clayton & Darvish, 1979; Parkes, 1965; Pitts, 1965; Stroebe & Stroebe, 1987).

However, it would appear that parents' perceptions of support during their grief have been given little attention. Whilst there is a growing understanding of what parents experience, there is little empirical research to show whether provision of support or lack of support affected the parents' distress or ultimate readjustment; or indeed whether parents feel adequately supported either by society, professionals or voluntary organisations. Furthermore, whilst the need for support for these families is implicit in the bereavement literature, there are few suggestions as to which health professionals should offer it, other than those involved in psychology or psychiatry when it could be assumed that the bereavement has become more complex. It would seem, therefore, that help is only offered when complications set in. The International Work Group on Death, Dying and Bereavement (cited in Fulton & Bendiksen,1994) have considered assumptions and principles related to bereavement. One of the assumptions that they include is: that the family system and its usual dynamics may be disrupted and changed by the loss of a family member, in which case the principle suggested is that:

> the care-giver should, when necessary, be ready to assist grieving families as they adapt to changes in organisation and relationships related to the death (cited in Fulton & Bendiksen, 1994:418).

There is no mention of who this care-giver should be.

Whilst cot death (SIDS) up until the early 1990s was one of the commonest causes of sudden childhood death during the early months and first year of life, the mortality rate from such a cause has dropped dramatically in the last eight years, this decrease being mainly attributed to the "Back to Sleep" campaign launched in 1991 (Fleming 1996).

Deaths later in childhood as a result of accidents and unexpected illness have attracted far less interest from researchers.

Bereavement can be viewed as a social network crisis in which it has been noted that:

> The vacuum created through the loss of a significant relationship, especially in a closed network, will draw the entire group into distress. The joint experience may render network members unable to support the individual for whom the loss is most immediate and profound (Stylianos & Vachon, 1993:397).

In addition, friends and even other family members are often likely to respond by pointedly avoiding the subject and also by reducing contact (Gorer 1965, Foster & Smith 1987). As a consequence, parents, unprepared and lacking social support, typically respond to their bereavement and to the unexpected social isolation that follows, with bewilderment accompanied by a devastating sense of personal loss (Mulkay, 1993).

Different sources of support may vary in effectiveness in different circumstances. Suggestions from family and friends may be perceived as criticism, whereas the same or similar suggestions made by professionals may be viewed as neutral expressions of helpful concern (Stylianos & Vachon, 1993). The perception of disapproval from primary others can become a source of ongoing strain or conflict that may generate shame or guilt, frustration and/or despair (Thoits, 1983). However, Aries has suggested that society has reached a point where death is denied and so chooses to behave as if death did not exist.(Aries 1981:92):

> where a single person is missing for you and the whole world is empty, but one no longer has the right to say so aloud (Aries, 1981:92).

Thus it is difficult to see the way ahead. Over thirty years ago, Gorer claimed that:

> the majority of British people are today without social help in living through and coming to terms with grief and mourning (Gorer, 1965:110).

Parkes, twenty years later, still maintained that bereaved individuals get little support from society at large and from their own families in particular (Parkes 1986:30).

One of the major changes which has taken place since Gorer's statement has been the development of increasing numbers of voluntary bereavement agencies. This raises several questions. Are they recognising a need met in the past from other sources? Do bereaved people attend groups because they have no social network to support them? Walter suggests that both may be involved: the collapse of traditional community and the breakdown of understanding within the nuclear family (Walter 1994:192).

There is also the question of whether bereaved parents turn to agencies because bereavement care is not considered part of the role of the health service, especially the primary health care team, either by team members or bereaved parents. And for those who do not use bereavement agencies for whatever reason, what else is available to them?

It would appear that it is only at times of sudden, unexpected tragedy on a large scale such as Aberfan, Hillsborough, and Dunblane that death enters the public domain and generates transient interest, the "pornography of death" as suggested by Gorer (1965:169) when the actual bereavement of the survivors would seem less important

than the awfulness of the event. And yet, Stroebe et al (1993) from the field of psychology, have noted that bereavement has far-reaching implications:

> It is a concern that extends beyond the boundaries of clinical interest, the domain from which much of the early research drew its impetus. It affects at some point every family and raises logistic and policy issues for the health and social service agencies of every community (Stroebe1993:3).

Whilst their comment concerns bereavement generally, in discussing child death specifically, Mandell(1987:750), a paediatrician from a medical background, has suggested that:

> We as health professionals need to develop insights into those moments when the human barrier cracks open to reveal what is most secret and inarticulate. We should be able, through the same rigorous attention to detail as we use in the biomedical context, to lend our strength to our patients and families when their strength is at its lowest ebb (Mandell, 1987:750).

It is noted that Mandell includes the family in his concern. There is now an increasing interest in the impact of bereavement not only on the individual most affected (spouse, parent etc.) but on the small group, notably the family (Rosenblatt, 1993; Shuchter & Zisook, 1993). Individual reactions are strongly moulded by those of the family. Thus, the family may send messages to set aside grief following a cot death which may encourage the adoption of a facade of functioning but may engender resentment and isolation (Rubin, 1993).

Clearly it is important to understand the family context in which grief takes place, to extend care to those in the close family, and to develop ways to measure and assess family reactions and their interplay. Archer (1995), in his review of the "Handbook of Bereavement" (Stroebe, Hansson & Stroebe, 1993) described it as a collection of well

known authors in the field of grief and characterised the text "as a landmark for researchers and practitioners interested in grief" (Archer, 1995:477). With the exception of a chapter by Rosenblatt (Chapter 7) on the social context of private feelings, the book has a conspicuous lack of empirical and theoretical work on family grief as a phenomenon in its own right and as a critical dimension of grief today. The chapter on the death of a child (Rubin, 1993) concentrates essentially on the grief of parents, and whilst it gives valuable insights into the complexities of grief in bereaved parents, there is no mention of others in the family.

Few would dispute the potentially distressing nature of childhood death, but it may be inaccurate to suppose that all families who undergo such an experience will require or even want support from outside agencies. Research into other forms of stressful life events suggests that the majority of individuals exposed to highly threatening and disruptive events appear to escape serious psychological impairment (Monroe and Depue, 1991; Krupinski and Burrows, 1986; Vachon et al, 1982). Therefore while it is reasonable to expect that the death of a child may lead to disruption in terms of mental health, changed marital relationships, and greater isolation, this may not be the case for all families.

However, at the present, there is no recognised system which allows identification of families who require more help from the time of death. It would appear that it is only when the bereaved have difficulties in coping with their grief, that they are referred to a "specialist" professional.

It is recommended by the International Work Group on Death , Dying and Bereavement (1994) that:

> bereavement care should be delivered as effectively and as economically as possible and that all persons should have bereavement support readily available (cited in Fulton & Bendikson, 1994:420).

It would appear that while the principles are sound, the reality, especially for bereaved parents, is far from being achieved.

In other generations it would seem that support and care for the bereaved fell naturally to society, whereas the bereaved today, especially those who suffer the death of a child, tend to be left alone to cope as best they can. Chapter 2 of this thesis will consider the change in attitudes to death and bereavement since the Middle Ages which help to explain the current situation where the bereaved are left in isolation in Western society.

The following three chapters will consider the intra, inter and extra dimensions of bereavement from the perspective of understanding that bereavement is an holistic experience for each individual: Chapter 3 will look at how the psychological, physical and spiritual aspects of bereavement may affect adults. Most of the research in the field has concentrated on adult grief especially that of widows. How this coincides with the grief of parents will be examined using current research on parents' grief. Gender differences will be noted. As grief is a family affair, where children may be affected, how children view death, and how they may react after the death of a sibling will also be examined. Grandparents, too may be affected by the death of a child, so what literature

is available, will also be presented. Chapter 4 will then go on to consider the inter-personal dimensions of bereavement which involve the relationship between bereaved parents, difficulties they may have in communicating with surviving children, and with grandparents. Chapter 5 will examine the extra-personal dimensions of bereavement which involve support for bereaved families from those outside the close family such as friends, neighbours voluntary agencies, and professionals. Following this, in Chapter 6, there is an account of the methodology for conducting research into bereavement. The methods for conducting both Phase 1 and Phase 2 of this thesis will be detailed.

Because of the apparent gap in empirical research in considering support for bereaved families, the presented research has sought to determine in the first instance, parents' perceptions of care from their own social circle and family, and from the statutory and voluntary sectors, after the sudden, unexpected death of their child from accident or illness. At the same time, in the same area, the study has also established how confident health care professionals and members of voluntary agencies felt about the care they could offer to bereaved families. This is known as Phase 1 when the author was the project leader, in collaboration with a research assistant, a statistician and the Head of the Department of Child Health, Bristol University. The author was central to that project in constructing the methodology, in carrying out data collection and in writing the final report. Chapter 7, written by the author, will report the findings of Phase 1.

Using the findings from Phase 1, the major part of this thesis is Phase 2 which has been the sole work of the author. In Chapter 8, consideration is given to options available for improving support for families whose child has died suddenly. Health visitors would

seem ideal professionals for taking on a supportive role of bereaved families, and so have been targeted specifically in my research. The development of an intervention for health visitors, based on identification of stressors within the intra, inter, and extra-personal aspects was the method chosen and will be discussed in detail. The findings from the parents' questionnaires in Phase 2 of the research, a randomised controlled trial, conducted in one English region, will be presented in Chapter 9. This is followed in Chapter 10 by the results of the questionnaires from health visitors. The final Chapter will discuss the results and implications and draw conclusions from the findings.

CHAPTER 2

AN HISTORICAL PERSPECTIVE OF ATTITUDES TO DEATH AND BEREAVEMENT IN WESTERN SOCIETY

Introduction

It has been suggested that the death of every known individual has been one of the central facts of life so long as there has been human awareness of the human condition. However, this does not mean that, being so well known, it is not problematical. On the contrary, like history, death has required redefinition and new analysis virtually with every generation (Parsons, 1994:60).

The death of children unfortunately is part of life and brings its own acute suffering to those who experience it. The book of Genesis, written around 2000 B.C., is rich in descriptions of family themes involving loss. The account of Jacob's pain following the supposed death of his favourite son Joseph is one such example:

> And Jacob rent his garments and put sackcloth upon his loins, and mourned for his son many days. And all his sons and all his daughters rose up to comfort him; but he refused to be comforted; and said, "Nay, but I will go down to the grave to my son mourning." And his father wept for him (Genesis, 37: 34-35, cited in Rubin, 1993:285).

It would seem that the pain of a child's death is one of the most stressful and painful of life events where support from family and friends may or may not be helpful. However, although not related specifically to child death, Aries has suggested that contemporary society has now reached a stage where:

> death has been so obliterated from our culture that it is hard for us to imagine or understand it. The ancient attitude in which death is close and familiar, yet diminished and densensitised, is too different from our own view, in which it is so terrifying that we no longer dare say its name (Aries, 1981:579).

As a result, codes for allowing expression of feelings in consoling the bereaved, no longer exist (Aries, 1981). Furthermore, whilst traditional rituals present in past generations provided a framework within which feelings could be expressed, today, society has become informal and distrusts "empty" ritual (Elias, 1985:24). As Stephenson suggests (1994), the lack of a social structure in developed countries within which mourning can take place and the grief processes successfully worked through, can contribute to a sense of helplessness. Overwhelmed by grief, struggling to reorganise their thinking, mourners find that the social world offers no direction, no recognition of their plight.

It would appear that in other generations this was not the case, so what has produced the change? With the aim of understanding why support for the bereaved has diminished today in Western society, this chapter will consider changes in attitudes to death over the centuries which inevitably involve the support and care for those who mourn the loss of a significant person.

Death in the Middle Ages

It would appear that central to the reason for changes in attitude to death and bereavement, has been the control of the dying process and the place of death (Aries, 1981). In the Middle Ages, the control of death was held by the dying person who died

in the heart of their particular community. Up until the time of death itself, dying people had a key role to play in what were undoubtedly social proceedings, that of preparing themselves and others for their death, a "tame" death (Aries, 1981:15). Death was sad and inevitable but a natural end to life. At the same time during this period, sudden death, a death which happened without warning, was considered ignominious and shameful, especially when there was no witness to the actual death. Such a death destroyed the order of the world in which everyone believed; it became the absurd instrument of chance, which was sometimes interpreted as the wrath of God. Sudden death was seen as vile, ugly and frightening, "so strange and monstrous an event that nobody dared talk about it." (Aries, 1981:10-11). Aries is referring specifically to adult deaths but it could be assumed that the sudden death of a child produced the same reaction. Such a death marked the person with a malediction so that there was no ceremony for them, or their family. It could be assumed, therefore, that support for the survivors was greatly lacking. Christianity attempted to change this attitude to sudden death, but warily and with some confusion. For example, Durandus, a thirteenth century bishop, is said to have believed that to die suddenly was the judgement of God (Aries, 1981:11). However, someone who died in this manner, he believed, must not be regarded as accursed, as "the just man, no matter when he leaves this life, is saved." So long as an individual was not engaged in other but harmless activity before death, burial in a cemetery should be allowed. However there was no certainty that this would be the case (Aries, 1981:11). While sudden child death today is not surrounded by many of the complexities and beliefs of the Middle Ages, it continues to be an event which destroys

the order of the world for those closely involved, especially bereaved parents, for whom it would appear, there is little support available but for different reasons.

Attitudes to Death in the 15th, 16th & 17th Centuries

By the fifteenth and sixteenth century, sudden death was unusual but still greatly dreaded. Most people died in bed from a "natural" death, even when there had been a serious wound or violent accident, allowing time for ritual on the death bed (Aries, 1981:6). It was only when the plague became prevalent in Europe that sudden death became preferable to the expected and ritualised death. Death took its toll on both adults and children. The effects of the disease caused great suffering, and the dying longed for a release into death (Aries, 1981:123). By the seventeenth century, both sudden and violent deaths were seen as commonplace, preferable to long illnesses and considered "the greatest blessing that life could bring " (Aries, 1981:123).

Prior to the Industrial Revolution, most people in Britain lived in small stable communities, with shared activities and common needs. Kinship and community links were strong and economic activity and domestic organisation identical (Laslett, 1971:4). Central to this cohesive structure was a common religious belief and a church which provided a framework of social welfare and control. Death was frequent, but traditional customs and religious ritual provided opportunities for the bereaved to express their sorrow in a manner that made the grieving experience easier to endure and to complete (Jailland, 1989:180).

The Church gave the community specific guidance in supporting the bereaved. The maintenance of a grave gave a focus for grief and prayers and masses could be said for the souls of the dead. In such close communities, there were those who were considered "wise counsellors" to help the bereaved or "kinsfolk (who) might act to assuage internal strife by timely advice" (Houlbrooke, 1984:20). For those whose child had died, such available persons must have brought great comfort.

Attitudes to Death in the 18th Century

By the eighteenth century, control of death had moved to the dying person's family. Most deaths continued to take place in the home where bereaved family members could support each other. This appears to have been a time when death was romanticised, a great event, which confirmed and deepened the meaning of an individual's life. It was the deceased's life that mattered with a sense of nothingness beyond death. Death was considered a romantic, passionate and yet a joyous affair, tainted only by the pain it inflicted on those who remained (Aries, 1981:410, 610). Death, it would seem, by virtue of its beauty, had become an occasion for the most perfect union between the one leaving and those remaining behind. The last Communion with God and/or with others was considered the greatest privilege of the dying (Aries, 1981:612).

The Victorian Celebration of Death

As a result of cholera epidemics, infectious diseases of children, accidents in the workplace, and high maternal and infant mortality rates, death in the Victorian era was common, affecting most families. Tuberculosis was the most important single cause of death during this time which affected all ages, accounting for 4,000 deaths per million each year (Hart, 1985:5).

The Victorian celebration of death has been seen as a helpful rite of passage for mourners. For example, Gorer's study (1965) of society at that time, assumes that the Victorian era was a "golden age" for grief. The belief that rituals of mourning provided support and guidance for those bereaved is strong. As Marris has written:

> Traditionally, full mourning in England would begin with the shuttering of the house, and the hanging of black crepe, while the dead person was laid out in his or her home. The funeral procession itself was decked with as much pomp as the family could afford or its sense of good taste suggested. Thereafter the nearest relatives wore black for several months and then half mourning for a while, gradually adding quiet colours to their dress.....and when the period of mourning is over (the family) can take up the thread of life without guilt because the customs of society make this its duty (Marris, 1986:29-30).

Gorer (1965) suggests that the wearing of black which symbolised mourning, was helpful in that recently bereaved people were easily identifiable and therefore could be given support by the wider community. For middle class women, mourning dress of an exaggerated severity was worn for the first two years by the widow, as a sign of "inner desolation." However, it does not necessarily follow that as a result of identification, mourners were given more support by onlookers. It may well have been the case that they were shunned as today, so that isolation was increased. It is also questionable as to

whether individuals found it helpful to remain in mourning for at least a year after the death of a loved one, when they were partly excluded from society. The central involvement of women and the partial social death for them, required by the rules of Victorian etiquette, was not only a symbolic expression of loss (Mulkay 1993:39). It also served as a mechanism whereby the social existence of deceased family members was extended; for one of the primary tasks of bereaved women was to keep alive the memory of the family dead by means of regular prayers, remembering birthdays and anniversaries, and by visiting the grave (Morley, 1971; Walvin, 1986). Given the high adult and infant mortality rates of the period, the great majority of middle class women would have spent years enclosed within the ritual death sequences through which expression was given to the collective bereavement of their families (Mulkay, 1993). Thus it could be assumed that mourning customs were more punitive on women than on men. The relationship between rituals and social support is complex, although in the case of mourning customs at that time, it is difficult to separate them.

Recently, social historians have questioned Gorer's analysis of mourning during this time. Richardson (1988) and Cannandine (1981) have indicated that the Victorian celebration of death was unavailable for certain groups in society, groups where there was considerable financial hardship. Poverty was not uncommon, so that in death those who failed to provide for themselves, were taken naked, wrapped only in paper or a strip of calico. There was no funeral with pomp afforded to the more wealthy, so that poverty stricken relatives were denied any formal farewell and choice as to where the burial would take place.

The poor also suffered from other hardships. Mc Keown (1976) has suggested that the high mortality among infants, was either a direct result of starvation or a function of decreased resistance to infection brought about by hunger and malnutrition. In the absence of effective contraception, unplanned birth and unwanted children were commonplace. In such circumstances, very high infant mortality must in some degree have been the results of parents being forced to neglect or even abandon babies they could no longer afford to feed (Hart, 1985:32). It could be suggested that in such cases, death produced relief rather than grief; but guilt may also have featured strongly, producing a complex situation. Due to the high mortality rate of children, it was not uncommon, especially in the lower social stratum, for parents to experience the loss of at least one of their children and for young people to possess a vivid sense of death at an early age.

As death was so common, children as well as adults needed to be prepared. Contemporary children's literature performed this task by constantly rehearsing the death of the young in fictional form and by instructing readers how to conduct themselves in relation to death in the real world (Walvin, 1986). Equally important was the fact that most deaths normally took place in the home, so that children learned how to cope with the deaths of others, and implicitly their own deaths.

What is not so evident is whether people of the time actually grieved. Laslett (1971:249) is confident that "our ancestors were not different from ourselves, they were the same" although, as Houlbrooke points out, evidence is from the literate classes. He agrees that

families were as dysfunctional as families today and for them too, "the experience of loss was often bitter and hard to accept" (Houlbrooke, 1984:21). Stone (1984:80) alleges that earlier ages did not have close emotional ties, but this is disputed by Laurence (1989:21) who argues that grief was strongly manifested even for stillborn and new-born babies that died. Families were broken and reconstituted then as today, but by death rather than divorce. The difference between then and now lies in the framework and means of expression for the process of grieving.

Whilst the common religion in *Victorian times was predominantly Christian, other* religions considered mourning differently. While mourning is often conceptualised as a natural human reaction to loss, for Durkheim, of Jewish descent it was a requirement of group life. He believed that the nature of a person's integration into social life had an important effect on how the dispensability of life was viewed. Durkheim wrote of mourning at this time as:

> not a natural movement of private feelings wounded by a cruel loss; it is a duty imposed by the group. One weeps, not simply because he is sad, but because he is forced to weep. It is a ritual attitude which he is forced to adopt out of respect for custom, but which in large measure, is independent of his affective state. There is no connection between the sentiments felt and the gestures made by the actors in the rite (Durkheim, 1897:445).

This is consistent with Durkheim's basic assumption that emotional states and attitudes are representations of Jewish collective life and that society is the origin of such mental states (Owen, Markuson & Fulton, 1994:83). As the Jews have been a persecuted race throughout history, it would seem that their philosophy of uniting in adversity offers more chance of their survival. Hertz (1960), also Jewish, suggested that death always

presented a dilemma for society. The difficulty was not for the individual survivor who may be suffering from grief, but for the future well-being of the surviving members of the whole group.

This is in direct contrast to the Christian Roman Catholic notion where the pain of the survivor was intense, and more individualistic, the idea of future collective life being less important, as is demonstrated by a priest poet of the time.

> No worst there is none. Pitched past pitch of grief more pangs will, schooled at forepangs, wilder wring. Comforter, where, where is your comforting? (Hopkins, cited in *Poems*, 1967:27).

Sumner, an early American sociologist writing at the same time, shows how widows stand in sharp contrast to conditions imposed on the widower.

> The death of the wife is an incidental matter, as it appears, compared to that of the husbands; and the provisions as to the behaviour and destiny of the survivor leave the man, for the best part, out of account. Almost never is he forced to accompany his wife to the spirit world; he mourns but a little; he is not much limited in the matter of a second marriage. His lot, in short, is not materially changed by the event (Sumner, 1927 :1841).

It is unclear as to whether this is what Sumner believed or whether this was society's attitude. His remark would suggest that whilst widows were permitted to show their grief, their lives were changed greatly by the death of their husbands, presumably because of changed economic factors, as men were the chief bread winners. On the other hand, Sumner sees widowers being little affected by their wives' deaths and should behave as if it mattered little. It could be argued that the "stiff upper lip" adopted by men , and continues today, stemmed from this period.

The Twentieth Century

By the beginning of the twentieth century, the death of a person still affected the entire local community, involving its members in the funeral and in visiting the bereaved. The death of each person was a public event that moved, literally and figuratively, society as a whole (Aries, 1981:560). However, social change proceeded at an extremely rapid pace so that by Edwardian times, experiences of mass bereavement were less common (Littlewood, 1992). As public health dramatically improved, thereby lowering death rates, expectations and rituals surrounding death, changed. Optimism concerning the further potential for the rapid progress of society in general and medical science in particular, led to a belief that death itself could eventually be totally conquered, so that by implication, there would be no bereavement (Illich, 1977).

Gorer (1965) associates the decline of Victorian mourning customs at this time, with the onset of World War 1, suggesting that because death was so common and widespread, there was a decline in mourning mores. However, Cannandine's (1981) assessment is an interesting contradiction. He argues that the decline in mourning customs mirrored the decline in mortality rates, as the Edwardian era began. Indeed, the ethos of the late-Victorian and Edwardian public school produced an atmosphere in which games and soldiering were equated, in which death was seen as unlikely, but where if it happened, could not fail to be glorious. (Cannandine, 1981:195). It could not have been foreseen that such games were to become a harsh reality where many men were forced to die for their country.

World War 1

The advent of World War 1 meant that men so recently spared of early death from childhood diseases, were likely to die on the battlefields. Bereavement once again became a virtually universal experience, almost every family experiencing the loss of at least one adult male member as approximately 30% of soldiers died in action (Littlewood, 1992). With death so widespread, many shared the experience of grief. The old Victorian rituals were not revived, and indeed were not appropriate or feasible. Specifically the war radically changed the relationship between the corpse and the burial, the living and the mourners. A new order of mourning appeared, associated with large numbers of dead. Soldiers died away from home, so that there was no opportunity of seeing the dead body, or indeed of having a private funeral. For many there was the uncertainty of knowing whether their loved one was missing or presumed dead (Cannandine, 1981:214).

Following the War, there was a dramatic interest in spiritualism. Not surprisingly, because there was frequently no corpse and the uncertainty concerning the reality of the death, many turned for comfort to the spirit world. As Thomas illustrates :

> We say your departed certainly return, they often stand at your side as in former days, though not being clairvoyant, you do not hear them. They speak to you, but not being clairvoyant, you do not hear them. They try to impress you with an awareness of their presence, though you deem that sudden thought of them just a fancy of your own and nothing more (Thomas, 1928:194-5).

In the aftermath of such a terrible and violent war, the idea of eternal life must have seemed very appealing and comforting.

As the pomp and splendour of Victorian funerals was no longer appropriate, war memorials were erected throughout the country, even in small villages, to ensure that the dead were not forgotten. Armistice Day was created and is still remembered annually as public recognition of those who died both in World War 1 and World War 2 (Littlewood, 1992).

The inter-war years

By the late twenties and early thirties, Eliot, a pioneer sociologist in the area of death, contributed articles to a wide range of journals, focusing on the problem of familial adjustment to bereavement. He saw the area of bereavement as "a new field for research" and one which required the special skills of the social scientist. He enquired whether the time was ripe for "a mental hygiene of grief". He saw customs changing, but as he suggests:

> We do not know from actual personal evidence what practices, new or old, are comforting or under what circumstances they cause conflict (Eliot, 1932:115).

However, Eliot's call for a social psychology of death and bereavement and for research into problems associated with loss, remained essentially unanswered until after World War 2 when the sociology of death was to resume.

World War 2

In terms of rituals, those developed during World War 1 were similarly extended to World War 2, presumably because the circumstances were not sufficiently different to

warrant change. Whilst fewer men died on the battlefields than in World War 1, death reached greater proportions in a way previously unknown in history. In terms of global understanding rather than personal understanding, the situation changed dramatically. The mass murder of people in concentration camps and the horrors of Hiroshima and Nagasaki, left a legacy of the possibility of either intentional or accidental destruction of the world (Littlewood, 1992:34).

1950s The Beginning of Denial

Once the war ended, death became less common in developed countries, and thus bereavement became a relatively rare experience in comparison to previous times (Gorer, 1965). However, Gorer's analysis indicates an increase rather then a decrease in public interest in death, the new face of death, as he saw it, being one of dirt and shame. Death, and by association bereavement, was now the province of the voyeur rather than the hero. Gorer believed that a return to the Victorian way of mourning with Celebration of Death, with all the communal ritual involved should be revived; whereas Cannandine's (1981) analysis suggests that the public face of death was frankly exotic and vaguely romantic.

But by this time, the increasing power of the medical profession dominated the place of death. Most deaths took place in hospitals, and so the former role of the community in providing care for the dying and the bereaved was removed from society (Aries, 1981:570). The medical profession isolated death in the laboratory and the hospital,

from where any emotions could be banished (Aries, 1981:612). As the community felt less and less involved in the death of one of its members, because medical technology had taken over, society believed it was no longer able to defend the previous domesticated situation where people died in their own homes. At this point society lost its sense of solidarity, where responsibility for the collective life had been abolished, replaced by "an enormous mass of automised individuals" (Aries, 1981:613). Gorer's idea of returning to Victorian traditions was therefore unrealistic.

The Emergence of the Modern Hospice Movement

Increasing knowledge and understanding of the problems faced by the dying and their carers undoubtedly stimulated the growth of the modern hospice movement in 1967. Young (1981) characterised the hospice movement as having to face the taboo nature of death in order to overcome the fear of dying. He suggests that the hospice movement goes some way towards restoring death to its natural and dignified state rather than allowing it to remain associated with a daunting, dehumanising and frightening process. The hospice movement seeks to manage death in an open and participatory way rather than denying it or hiding it. James suggests that:

> notions of the family are integral to the principles of good terminal care and although the definition of "family" is not specified, it tends to be used in an idealised form (James, 1988:125).

There are three ways in which this family ideal is manifested in the hospice environment. There is a focus on the patient and their kin as the unit of care. Those who work in the hospice are encouraged to deliver care as if caring for their own family and

as a consequence the hospice community becomes the metaphorical family for the patients and their kin. The family ideology is present both within the philosophy and also in the organisation of relationships (Froggatt, 1997:130). The focus on the patient and their family is also related to the ideal of holistic care. The person is perceived as an integrated whole, rather than as someone of separate physical, emotional, social and spiritual parts. The patient is a social being with previously-established social relationships which cannot be ignored (Field & Johnson, 1993). Saunders described a hospice as:

> something between a hospital and the patient's own home; combining the skills of one with the warmth and welcome, the time available, and the beds without visible parking meters beside them of the other (Saunders 1977:160).

By the early 1970's, where possible and when chosen, death took place in a person's home rather than in hospital or a hospice building, thus allowing death to return to the community, albeit in a private way. Holistic care was practised not only for the patient but extended to family and friends both during the illness and in bereavement. Bereavement was acknowledged as part of the process of recovery, and care in bereavement was and is provided in the 460 adult hospices by a mixture of professionals and trained volunteers. Hospices for children with life threatening diseases began to spring up in the eighties, led by Helen House in Oxford. where the same philosophy as the adult hospice, was adopted.

However, Mellor and Shilling (1993) see the hospice movement in a less charitable light. In relation to palliative care which is more a medical concern, they suggest that

hospices are part of the "expert" society that adds to the privatisation/sequestration of death. However, in the wider sense, the more holistic principles employed by nurses and others, encompass the needs of all concerned, including family members who live on and who will no doubt be influenced by the way death was handled. It could also be suggested that the many volunteers employed by hospices may also be influenced by the hospice philosophy, thus spreading the concepts in society generally.

The complex nature of the differing influences on the hospice movement has resulted in a hospice concept which stands in contrast to the dominant ethos within health care, the fast turn-over, technological hospital devoted to cure (Froggatt, 1997). The hospice offers an alternative, anti-structural approach to the technology-dominated, individualistic, isolated death, away from family members, which is increasingly present in contemporary society. The ideals of "family" and "holism" are important ones which structure the experience of the care patients and their families receive. The hospice movement endeavours to create a space to manage the seemingly disordered process of dying and bereavement which may threaten order in society. In time the philosophy may spread, allowing the experience of "communitas" for dying and bereaved people, so constructing order in the potential disorder. However, for bereavement in particular, this model of care is only available at present to those who have had previous contact with a hospice. For those whose relatives die from other causes, both expected and unexpected, there is no formalised follow-up of care. As Faulconer (1993:70) points out, there is no clear government policy on the provision of bereavement services and consequently "a patchy and variable approach" exists.

Apart from death as a result of cancer, most deaths now occur in hospitals, where the dying are isolated from the everyday activities of the society in which they live. Present society would appear still to be ashamed and afraid of death, the dying provoking unease, embarrassment and disquiet (Aries, 1981). Consequently, the dying are removed from their local community to die in isolation away from it, such isolation extending to the bereaved after death. As living reminders of the unspeakable truth of death, the bereaved are avoided rather than supported, effectively quarantined (Aries 1981:580).

Social Change -Reasons for Isolation in Bereavement

Whilst denial of death may be the main reason for ignoring the needs of the bereaved, other radical changes have taken place in society in Britain during the last century which have altered the course of care and support following death. Modernity is the chosen word to characterise social, cultural, economic and political development in contemporary society. Ambler has defined the project of modernity as:

> the historic attempt to gain freedom and autonomy for man by gaining control over nature and society, first by understanding them analytically then by manipulating them technologically & organisationally (Ambler, 1996:143).

Applied economically, this approach has resulted in industrialisation with the consequent growth of cities. Viewed socially, it has fragmented communities into smaller units, (such as places of work, school and home) leading to possible isolation of individuals. The thirst for knowledge by questioning and seeking scientific understanding has resulted in less acceptance of, and more disintegration of the common

religious and social framework of past generations which gave shape and support to bereavement, providing the language and ritual in which emotions could be expressed.

Increasingly sophisticated technology, better nutrition, immunisation programmes and less over-crowding, have resulted in major advances in improved health and longevity. Before 1900, infectious diseases like tuberculosis, accounted for most deaths at every age, yet today they have virtually disappeared. Life expectancy in Britain has now risen from around 40 years in the first half of the nineteenth century to 75 at the end of the twentieth century (Moon, 1995:13). Death is no longer a common occurrence in people's lives, nor does it take place in the community. As Elias suggests: "never before..... have the dying been removed so hygienically behind the scenes of social life" (1985:23).

Adams (1993) argues that the increased value of male, scientific rationality, associated with professional training and the provision of formal care in the public sphere of the hospital, funeral director and male mortician are major factors in the decline of the role of neighbourhood caring. As a result:

> death no longer interrupts society and its values lose significance and the result is fragmentation of each generation from a sense of belonging to and identity with, a lineal stream of kinship and community (Blauner, 1966:391).

The kinship and community links available to past generations mentioned earlier in this chapter, are less available to present society. Mobility of families, with more independence of both young and old, lends itself to this change in focus, so that the

sense of community may no longer exist to provide immediate support, nor is the extended family as available as before (Worden, 1983:3). Walter (1996) believes that norms for talking of death are changing, different generations no longer knowing how to communicate with each other. For example, a religious grandparent, and an adult child who has learnt to be more expressive, and emotional, may find it difficult to communicate openly and easily.

Whilst segregation and fragmentation have affected the community, so too, has the culture of individualism. As Montgomery suggests:

> our society's beliefs and self-reliance, separateness and autonomy make caring a cultural embarrassment because it violates these values (Montgomery, 1993:119).

The church which played a major part in everyday life appears now to be irrelevant to many. Libby (1988) in a nation -wide survey showed that only 10% of the population in 1986 regularly attended church and 47% described themselves as "fairly" religious (57% in 1966). In 1966, 53% of people were certain there was a God, reducing to 42% in 1986.

Mourning is now expected to be done in private, where, as Gorer suggests:

> one mourns in private as one undresses or relieves oneself in private, so as not to offend others (Gorer, (1965:113).

If mourning is considered a social act, privatisation means that mourning disappears, leaving the bereaved with their own private grief. It would seem that the Victorian

celebration of the intense emotions of grief and the romantic cult of the dead has given way to a modernist and medical concern to return the individual as rapidly as possible to efficient and autonomous functioning (Stroebe et al, 1992).

From the bereavement literature, it would appear that the informal nature and the loss of traditional social and religious customs create an environment in which talking to the bereaved and allowing expression of feelings is more difficult. It is therefore more comfortable to avoid the bereaved, to disclaim any responsibility and to hope that others will have the expertise to respond to the situation. This would seem to be particularly true for those whose child has died, as child death is no longer a common-place event. Mourning behaviour norms may provide a structure within which the grief-stricken can own up to their feelings and acknowledge their loss, but the lack of social structures within contemporary society, forces individuals to cope alone as best they can with grief.

As the concentration of death among the elderly has become firmly established and has come to be taken for granted, so the death of the young has come to be almost unthinkable (Mulkay, 1993). But this rarity means that parents are set apart to forget, and to prepare to replace the dead (Mulkay 1993). Their social exclusion is like that experienced by the very old, another expression of the customary flight from death in our society by those who are not directly affected. (Kearl, 1989). This being the case, families whose children die suddenly will have few support structures to help them through the ordeal.

Summary

Until earlier this century, the control of death was with the dying and their family when death took place in people's homes, the bereaved being helped and supported by their local community. This was certainly the case in the Victorian era when death affected most families. However, whilst this period has been viewed as a "golden age" for grief, it had definite limitations. The rituals of the period may have provided some comfort for mourners, but this was only available to the more wealthy. Women especially were expected to remain in mourning for at least a year, being excluded from society during that time.

As public health improved so bereavement was less common but the advent of World War 1, meant that many families were bereaved and were united in a common experience. The fact that often there was no body to bury may have made it harder for the mourners to accept the death.

As medical knowledge of disease, and medical power and expertise grew, so by the 1930's most deaths took place in hospitals which meant that both the dying and the dead were removed from the local community. Control of death was now held by the medical profession who concentrated on the physical manifestations of disease solely. As a result, society gave up its responsibility for its dying and bereaved, so that by the 1950's denial of death and implicitly the bereaved, had begun.

However, the emergence of the hospice movement in the late 1960's recognised the importance of treating both the dying and their relatives in a holistic manner. More people were able to die in the their own homes, thus returning death to the community. Bereavement care was a continuing part of care, and so for those families whose relative had died of cancer, mourners were given support, and not left in isolation. The effects of the hospice philosophy are now extending and it may be in time that its concepts may continue to influence society at large.

Whilst denial of death is one reason for excluding the bereaved, other changes in society have also contributed. Medical science has developed rapidly allowing more people to live longer, so that society now expects longevity. Children now die relatively rarely and so when they do, there is no clear understanding of how to behave and how to help the survivors. Through greater mobility and industrialisation, society has become fragmented and segregated, so that there is less community cohesion, resulting in less support for the bereaved. The established Church, which played a significant role in helping the bereaved in other generations, has now become obsolete for many who hold less conviction in an after-life which may have brought comfort in the past.

With so many changes in society and in the attitudes to death, it is clear why the bereaved, especially those mourning the death of a child, have become isolated. Thus the next three chapters will consider the difficulties that families face when a child dies, to demonstrate the importance of providing support for them.

CHAPTER 3

THE INTRA-PERSONAL ASPECTS OF BEREAVEMENT

Introduction

Few life events have a greater impact on a family than the death of one of its members. Most of what we know about grief is from an individual perspective because most studies have focused on individuals. Although grief is not a new phenomenon, it is only in this century that empirical studies have been undertaken to unravel the complexities of the experience. Most early research has concentrated on widows' grief, demonstrating that grief is a painful process which takes to time to recover from. More recent research has demonstrated the impact of grief on bereaved parents and that bereaved children also grieve. In the case of a child death, each affected member will have their own unique reaction to the death, but the family system may also be changed as a result of the death. It has been noted that adding or subtracting even a single member of a family has dramatic implications for the structure of the family (Broderick & Smith, 1979), so inevitably when a child dies suddenly, other close members may be affected and may be influenced by each others' grief. Therefore as Muxen (1991) suggests, it is essential to see the family as:

> a set of intimately connected people who are mutually influential on each other in some way and whose relationships evolve over time interactively with each other as well as with past, present and anticipated future contexts (Muxen, 1991:16).

Bereavement is also a social network crisis (Stylianos & Vachon, 1993), in which the joint experience of suffering may render network members unable to support a family whose child has died. The structure and quality of a social network may thus facilitate or interfere with the provision of social support. Although social support systems are potentially helpful, they may also be a source of stress (Gottlieb, 1983; Lehman, Ellard & Wortman, 1986; Wortman & Lehman, 1985; Wortman & Silver, 1989). Shinn et al

(1984) have emphasised that negative interactions that derive from supportive efforts are actually additional stressors, not just indicators of a lack of social support. Such negative interactions may potientiate the effects of other stressors.

Thus it can be seen that when a child dies, there are three main areas that may cause stress to the family. Firstly, the event may provoke an internal reaction in each member, that is intra-personally. Secondly, the death may cause a change in family relationships and dynamics, that is, inter-personally; and finally the family may be affected by the attitude of others outside the close family, that is, extra-personally.

In the first of three chapters on the stresses that a child death may provoke within a family, this chapter will consider the intra-personal aspect, that is, the effect that the death may have on individuals. It will firstly consider how adults are affected by death, particularly bereaved parents, and will look at any differences between fathers' and mothers' grief. Secondly, it will go on to explore children's understanding of death and how they may react when faced with the death of a sibling. Chapter Four will look at the inter-personal dimension which involves possible reactions between family members. The intra and inter aspects inevitably are linked together, so while an attempt has been made to separate them, both Chapters Three and Four contain elements of each. Chapter Five will then consider the extra-personal aspects which may hinder or help a family's grief.

The Psychological Effects of Grief on Adults

The first intra-psychic theory of grief was proposed by Freud in his treatise, "Mourning and Melancholia" (1917) and has stood as a precedent for scientific investigation into grief today. While he includes mourning in his discussion, Freud's main interest was in depression, not in the phenomenon of grief, as it was considered a normal response in

the course of everyday life at that time (Freud 1917b, 1957). He defined "normal grief" as a process that one must work through to free oneself of the attachment to the deceased, requiring much psychic energy in adjusting to life without the loved one. Empirical study of adult grief was pioneered by Eliot (1932), an American sociologist, who described typical reactions to grief as well as successful and unsuccessful patterns of recovery. Fulcomer (1942) building on Eliot's work, was the first to describe grief in stages, beginning with shock and ending with re-patterning in which the individual established a new and stable way of life. Lindemann's classic study of survivors of the Coconut Grove Fire in Boston (1944), described normal grief as having somatic and psychological dimensions. Like Freud, he believed that the pervasiveness of the loss experience, especially if it involves the untimely death of a close relative, proceeds to disturb the daily pattern of living. He suggested that the symptomology of acute grief included somatic distress, preoccupation with the deceased, guilt, anger and loss of usual pattern of living.

Research regarding the nature of bereavement has progressed from many different theoretical perspectives. However, the descriptive literature regarding the experiences associated with grief is remarkably similar (Littlewood, 1992). This apparent uniformity persists despite the fact that, as Bowlby (1980) notes, information about grief has been gathered for different purposes, using different methods, by different people. Experiences of grief are multiple and varied. It is difficult to organise them in terms of logical sequence of events. However, major researchers in the field have suggested that grief may be conceived in terms of stages or phases. At the risk of over-simplification, Table 1 shows the similarities of the stages by different researchers:

Table 1 Stages of Grief				
	Researchers			
	Averill (1968)	**Kubler Ross (1969)**	**Parkes (1972)**	**Bowlby (1980)**
Stages	Shock	Denial	Numbness	Denial
	Despair	Anger	Pining	Anger
	Anger	Bargaining	Depression	Despair
		Depression	Recovery	Stability
		Acceptance		

The attraction of stage/phase models may well lie in their ability to represent the experiences of bereaved people in a culturally acceptable manner, that is, as an experience which follows an ordered linear progression, resulting finally in resolution. As Littlewood (1992) suggests in evaluating stage theories of bereavement, it should be noted that the stages are not invariable nor necessarily adaptive. Individuals may oscillate between stages and not everyone progresses at the same rate over time, sometimes missing stages altogether.

However, grief is not a linear process with concrete boundaries, but rather a composite of overlapping, fluid phases that vary from person to person, dependant on many other variables, both situational and personal (Sanders,1989; Shuchter and Zisook, 1993). Therefore stages are meant to be general guidelines only and do not prescribe where an individual "ought" to be in the grieving process. Wortman, Silverman & Kessler (1993) see the stage theory as useful in a descriptive sense but argue that the major weakness of this theoretical approach is that it proposes no specific mechanisms through which loss may exert an influence on subsequent mental or physical health.

Physical Manifestations of Grief

As Fontana (1989) explains, the body's reaction to any situation of stress will cause a release of adrenalin and noradrenalin into the blood stream. If this continues long term, there is danger of heart disease and strokes, kidney damage and disturbance of blood

sugar levels thus increasing the likelihood of diabetes. There is also a release of thyroid hormones, increasing the rate at which energy can be burnt and translated into physical activity. If this continues, exhaustion, weight loss and eventual collapse may ensue. Cholesterol is also released into the blood stream from the liver which boosts energy levels and aids muscle function. Constantly elevated blood cholesterol levels may lead to arteriosclerosis.

Lindemann's early paper (1944) described not only the feelings that people experience but also the physical sensations associated with their grief reactions. As Worden (1983) suggests, these sensations are often overlooked, but they play a significant role in the grieving process. All or some of the following may be present: tightness in the chest and throat, hollowness in the stomach, breathlessness, weakness in the muscles with lack of energy. Certain specific behaviours are also associated with normal grieving: sleep and appetite disturbances (Littlewood, 1992), absent minded behaviour, dreams of the deceased (Littlewood, 1992), sighing, searching and calling out and crying.

It is not unusual for the bereaved to want to withdraw from other people, which may include a loss of interest in the outside world such as not reading newspapers or not watching television (Worden 1983). The value of this knowledge lies only in the fact that it is useful in helping the bereaved to know that such changed behaviour, or physical symptoms are normal. Bereaved individuals may have no fore-knowledge of this, and for this reason, professional support may offer reassurance or ways to decrease symptoms. It is likely that if an individual's mental or physical health is tenuous before the death, the stress of grief will exaggerate the condition during bereavement. Early studies showed an exacerbation of congestive heart failure and hypertension when individuals were faced with the threat of grief and loss (Chambers & Reiser, 1953; Weiner, Thaler, Reiser & Mirsky, 1957). As Sanders suggests (1993), individuals are more likely to volunteer information regarding their physical problems than their

emotional ones. There is evidence that people who have used health services frequently before the death of a loved one are most susceptible to poor bereavement outcomes (Mor, McHorney, & Sherwood, 1986).

The Spiritual Aspect- The Meaning of Life/Death

The concept of spirituality has traditional associations with religion (Stoter, 1995), and yet Laburn (1988) has suggested that the spiritual nature of man is the total personality which links aspects together, and is expressed through relationships, personal practices and beliefs. The spiritual dimension has also been described as:

> a unifying force that integrates and transcends the physical, emotional and social dimensions. It enables the search for meaning in life and provides a common bond between individuals, an essential ingredient for any relationship (Socken & Carson, 1987:603).

Spirituality encompasses the whole range of a person's life experiences and is influenced by these experiences. Hence, the nature of spirituality and the way in which it is expressed will vary with a person's background and culture in the context of the framework of his/her particular beliefs (Stoter, 1995). So the expression of need is unique to each individual.

It would appear that scant attention has been paid to the spiritual dimension of parents who experience the death of their child, as the literature search revealed little. The death of a child in the Western world, is fortunately a fairly rare event. When a child does die, then it is understandable that parents might question its meaning. As Adler has commented:

> Human beings live in the realm of meanings; we experience reality always through the meaning we give it, not in itself, but as something interpreted (Adler, 1958: 1).

The struggle to find answers, which is the search for meaning, is central to the grieving

process (Nadeau, 1998). In her study "Families making Sense of Death" (1998:188) Nadeau found that many of the respondents indicated that they held God responsible for the death of their family members. Some felt that it was a punishment for past wrong-doings, others were angry that God had let them down. Not all were religious, but most wanted to blame some outside force.

However, Shapiro (1994) contends that adults, children and families search for the cause of death in an attempt to integrate the death into their lives and to regain a sense of safety and order in the world. In other studies of parental bereavement, couples were asked about meaning associated with the death of their child (Heil, 1993; Lang, Gottlieb & Amsel, 1996; Wheeler, 1993). For these couples meaning or meaningless of the event mirrored Frankl's notion (1959), as portrayed in his book "Man's Search for Meaning", as the meaning or purpose of life, not the meaning attached to the particular death. Sedney, Baker and Gross (1994) drew on their experience as family therapists to present the notion that bereaved families make sense of their experience by telling the story of the death. These authors made a case for how listening to families' stories is a means to assess families and to gauge their progress as they grieve for a family member. They suggested that by asking families to tell the story of the death, the bereaved can be helped to gain emotional support, make their experience more meaningful and bring the family together. Thus it can be seen that the spiritual dimension, the meaning of life, is an important aspect of the grieving process, and should be included in any assessment of a family's needs.

The above sections have shown that bereavement is an holistic experience, involving not only the psychological aspect but also the physical and spiritual dimensions. Whilst the research in developing the various stages was largely based on spousal grief, especially widows, can it be assumed that bereaved parents who are also adults, will experience similar reactions?

The Effects of Grief on Bereaved Parents

As in the research conducted on spouses, shock, numbness and denial of the death have commonly been found in parents whose children died suddenly and unexpectedly (Cornwell 1977; Baumer, 1988; Lehman & Wortman, 1987; Mandell, 1987; Kennell, 1970; Defrain & Ernst, 1978; Friedman, 1974; Clyman, 1980). But in contrast to the adult spouse models, parental guilt and helplessness are central to their grief, and are mentioned by all of the above researchers. It would appear that grief in sudden traumatic death lasts longer than in expected deaths.

Sanders (1979) carried out a study comparing adult bereavement in the death of a spouse, child, and parent. She interviewed 53 bereaved spouses, 35 adults whose parent had died, and 14 parents whose child had died. She found that those who experienced the death of a child revealed more intense grief reactions of somatic types, greater depression, as well as anger and guilt with accompanying feelings of despair, than did those bereaved who had experienced the death of either a spouse or a parent. From her analysis, it would appear that the death of a child results in loss of emotional control by the parents, which exposes them to greater vulnerability of external influences (Sanders, 1979:317). A comparison of the long term effects of losing a spouse or child in a motor vehicle crash from sudden death, found that both spouses and parents showed clear evidence of depression and lack of resolution 4 to 7 years after the death had occurred (Lehman and Wortman, 1987). All the respondents in their study suffered losses that were unexpected and untimely which may have accounted for the difficulties in bereavement. A death without warning may shatter a person's assumptions that the world is orderly, rational and fair (Parkes & Weiss, 1983; Wortman, 1983). For this reason, those who suddenly lose a spouse or child through death may be more preoccupied with thoughts of how the death could have been prevented, so that the associated guilt feelings may take longer to resolve.

There is general agreement that sudden, unexpected death produces a shock that has a debilitating effect on survivors, which both prolongs grief and produces excessive physical and emotional trauma (Brown & Stoudemire, 1983; Lundin, 1984; Parkes and Weiss, 1983; Rando, 1984; Raphael, 1984; Sanders, 1979). Glick et al (1974) found that sudden death was seen as such a shock, that the capacity to cope was diminished and full functioning was not realised by some, even 4 years after the death. Sudden deaths cannot be predicted and therefore cannot be prepared for in advance.

In a study of 45 American parents whose children had died 6 months to 4 years earlier, Hazzard, Weston & Gutteres (1992) found, using the Grief Experiences Inventory, that parents whose children who died suddenly and unexpectedly, experienced more despair, anger, guilt and depersonalisation than those parents whose children died expectedly. Parents whose child died suddenly but who had more social support after the death, reported fewer atypical grief reactions. The study suggests strongly that professionals are perceived as important sources of support both during and after the death and that provision of support in general may decrease the likelihood of parents experiencing atypical or maladaptive grief reactions. These findings are similar to those found by Fish (1986).

The work of Bergman et al (1969) described the acute phase of family reactions to the sudden death of a child and emphasised that feelings of disbelief may last for several weeks. They further stated that other common reactions include anger, helplessness and loss of meaning of life and guilt was universal and pervasive. They noted that parents feared they were "losing their minds" and often there were major disruptions of routine behaviour. Friedman (1974) suggested that what bereaved parents were describing were intense, disruptive and almost intolerable grief reactions. He saw death by accident deserving special attention in that the parents, or an older sibling, may feel directly responsible for the fate of the child. He believed that the resulting grief may be

persistent, especially if, in reality, the accident might have been prevented by better judgement or supervision by the parent or sibling responsible for the child's safety. He further states that of primary importance in the unexpected death of a child, is the realisation that even though the death was sudden, the adjustment to the loss takes time. He considers support during the period immediately after the child's death as being important but does not eliminate the need for counselling later. The sudden loss of a child may be viewed as the beginning, not the end, of major adjustments that must be made by the surviving family members (Friedman 1974).

Watson's study (1981) of 308 families in Great Britain showed that 70% of the parents who had suffered a cot death experienced acute distress with anger, bewilderment, self-blame and anxiety when seen in the first few days. A second interview three weeks later showed that the distress had lessened to some degree in half the families, although it was still apparent. It seems that at this stage although in a state of crisis, parents are more able to verbalise their feelings and concerns. Lowman (1979) found that while a bereavement index score was high for the parents in his study in the first two months, it had settled to much lower levels by the follow-up visit at four to five months. Cornwell (1977) also found a lessening in acute feelings, but at twelve months after the death, parents were still primed to their baby's image.

As a distinct category within the field of adult loss, bereaved parents both overlap and diverge from that of a spouse loss. But even within this category there may be different patterns, due to gender differences.

Mothers' and Fathers' Grief

The death of a child is probably one of the most severe stresses that parents will experience (Defrain & Ernst 1978). Until recently, it would seem that the focus of

attention after the death of a child has been the mother. However, fathers are now more involved in child rearing than before and may develop closer bonds with their children. Sometimes the birth of a child reshapes his world, altering images of himself, his partner and his parents. A new father may be influenced and may be affected by the development of his child (Mandell 1979). As Mandell (1980) has suggested, it is important, therefore, to be aware of affectional bonding between children and their fathers and to be sensitive to the effects of the sudden, unexpected shattering of that linkage.

Although bereaved parents share the same loss, there is now sufficient evidence to show that mothers' and fathers' grief reactions are different. In Cornwell, Nurcombe and Stevens' study of 19 families in Australia, who had experienced a sudden infant death (1977), it was found that the usual pattern of family reaction was that the father's grief was less intense and resolved sooner than the mother's. The father's mourning was mixed with his wish to protect and comfort the mother. Sometimes the difference in length and intensity between the mother's and father's grief led to misunderstanding. The father accused the mother of unnecessarily prolonging the mourning when he wanted to forget about it. They found that marital disagreements, leading to arguments, were common. The greatest difference between parents of either sex was in the length of time taken to resume normal functioning; for mothers, the average time was 10.3 months, and 3.6 months for fathers. However in Defrain & Ernst's study of 32 parents in Nebraska, Western America (1978), families took an average of 8.3 months to regain the level of family organisation they held prior to the death. For some parents it took an average of 15.9 months to regain the personal happiness they had prior to the death. The majority of these parents (69%) suffered personal guilt and over a half, numerous other psychological and/or physical difficulties including insomnia, anorexia and nervousness. They also found that relationships with other family members were affected in various ways in the majority of cases.

Studying 28 bereaved fathers in Boston, Mandell, McAnulty and Reece (1980) found that the fathers felt the need to keep busy with increased work. They experienced feelings of diminished self- worth, suffered from self- blame because of lack of care and involvement and had a limited ability to ask for help. Denial was also evidenced by their wish to have other children as soon as possible and by their avoidance of professional help that would involve acceptance of their loss.

Dyregrov & Matthiesen's study (1987) of 55 families in Norway, who had lost a child over a period from 1 to 4 years showed that mothers reported significantly more anxiety, self-reproach, sadness, intrusive thoughts about the child than did the fathers. They also found that in terms of long-term adaptation, mothers experienced lasting emotional and physical problems. The experience of guilt feelings appeared more frequently in mothers than fathers. The researchers were unsure as to what caused the differences but put forward four main possibilities: they may be caused by a difference of attachment or "bonding" to the child, they may reflect different reactivity to stress or different methods of coping in men and women, they may arise because men under-report or fail to acknowledge emotions and reactions or they may reflect the different social situation the two sexes experience after the death. The researchers suggest that the large proportion of both fathers and mothers indicating strong to severe reactions after the death of a child, should lead health care professionals to be sensitive to the presence of these reactions, in order to facilitate care and support for these families.

It would appear that women find it easier to share their feelings, having a greater willingness or need to "recognise, label, express and disclose feelings." in contrast to the "tragedy of the inexpressive male" (Duncombe & Marsden, 1995:151). This may be the reason why in Riches and Dawson's study (1996) in the U.K., they found that more women than men work in bereavement support networks, that is, in local support

groups, grief counselling services, bereavement conferences and established bereavement centres. In their sample, they found that bereaved women were more available for interview, and were more prepared to talk candidly of their feelings and their marriages, even when their partners were present. They suggest that women do not necessarily feel their loss more painfully than men, but are more prepared to express it. As in Vance's study (1993) in Australia, mothers demonstrated that on average, they were 2.5 times more likely than fathers, to report that their relationship with their partner was less satisfactory.

Despite the fact that men find it harder to share their feelings, there is evidence to show that fathers do experience their grief emotionally, but they prefer to express it unobserved. As one father commented in response to his wife's comment that he had hardly cried at all:

> That's all you know. We've this shed at work, and there would be times I would lock myself in and just roar (Riches & Dawson 1996:143).

It seems reasonable to suggest that professionals may be unaware of fathers' deep pain because fathers choose not to show it, leading professionals to believe falsely that men do not grieve so intensely.

Vance et al in Queensland, Australia (1993) showed that parents affected by stillbirth, neonatal death or sudden infant death manifested high levels of anxiety and depression after the death. They found that mothers had more symptoms than fathers and parents affected by SIDS had the most symptoms of anxiety and depression. While they had anticipated that parents would report such symptoms, they were surprised at the frequency with which they occurred, as well as the high level of psychological distress in grieving families, even if members did not present with anxiety and depression. This has important implications for the recognition of symptoms and the support of bereaved families by support groups and professionals.

Bereaved Single Parents

The literature search revealed few studies on the grief reactions of single women who are faced with the death of their child. However, the study carried out by Ostfield, Ryan, Hiatt,and Hegyi (1993) demonstrated that single women whose children had died from a cot death, are at the greatest emotional risk, experiencing higher levels of grief and reporting fewer support systems. There is no mention of single bereaved fathers. Due to the paucity of research into this area, it would seem appropriate that further studies are conducted.

While there is evidence to show that bereaved parents experience a range of feelings similar to those identified in spousal bereavement, there is wide diversity especially between mothers and fathers, mothers tending to be more open in sharing their feelings than fathers and also taking longer to adapt to the tragedy.

However, in a family where a child dies, there may also be surviving siblings. What understanding do children have of death and how are they affected? Grandparents, too, may be deeply affected. How will they react? The next section will consider these questions.

Children's Understanding of Death

Until recently the assumption has been made that children understand little about death and should be protected from its harshness. As Morgan, a Canadian philosopher, stated:

> We tend to assume that the life of a child consists of little more than the gathering of memories that in later years can be recalled fondly. In reality, nothing could be further from the truth. Childhood is, and always has been, a time of trial and loss (Morgan, 1991:xv).

Young children live in a world that can be both lyrical and frightening, rich in poetic imagery and yet stark in its frightening realities. Some trivial events can bring delirious joy and excitement to life; other trivial events in comparison can produce painful

feelings of fear and abandonment. They may meet the death of a relative far less frequently than their fore-bearers, but they meet loss in many forms; the death of their parents' relationship, divorce, redundancy, unemployment, changing schools, the death of pets and the loss of friends who move away (Morgan 1991:2).

Whilst a child today in the Western world may not be exposed very often to the death of a close family member, there are other deaths that may be experienced, such as a relative, a neighbour, and sometimes a class mate. Many will witness the death of animals. These experiences will trigger many questions that deserve honest answers (Wass & Corr 1984). If a child is kept in the dark, a powerful message is conveyed to the child, that death is "such a horrible thing that it must not be mentioned" (Aries 1983:10). Younger children's understanding of death is often complicated by the attempts of others, especially parents, to protect them from raw knowledge, so that they may struggle to reconcile their own current assumptions and the variety of magical and evading accounts presented by others (Raphael 1984).

The advent of television has played its part in giving confusing messages to children about death. As Corr has suggested:

> As direct personal experience with death has become more limited, indirect experience through the media, especially television, has vastly increased. The view of death presented by television programmes is highly distorted. Often death is portrayed as something that does not happen at all (as in "Bionic Man") When death does occur, it is often without visible pain, or tears (Wass & Corr 1984:3).

It is now known that children's understanding of death depends on several factors: their level of cognitive development, their experiences and their perception of events in the world. It is also recognised that children's thinking is qualitatively different from that of adults and that concepts of death usually develop in an orderly sequence (Wass & Corr 1984:5). This sequence proceeds from non-conceptualisation of death in infancy, to the concept in late infancy and early childhood that death is a reversible event, a temporary

restriction, departure or sleep, to the comprehension during middle childhood and pre-adolescence that death is irreversible, universal and inevitable (Wass & Corr 1984).

Nagy's research on Hungarian children (1948) demonstrated that there are three stages in a child's conception of death. In the first stage, at approximately three to five years, death is seen as a departure, with the deceased maintaining an existence somewhere else, the finality of death being denied. In the second stage, between the ages of five and nine, death is personified; that is, it exists but can be avoided. Only some children and some adults die. In the third stage, at the age of nine or ten, death is understood to be an inevitable event that happens to all people; it is understood realistically. According to Rosen (1986) it is important to note that comprehension of the finality of death may come in two stages; first, an appreciation that others can die develops, and later, a recognition that the child himself can die, is achieved. Stage one may precede stage two by as much as a few years, evincing a phenomenon that underscores the strength of the child's ability to use denial.

However, more recent researchers have found strong evidence to show that at least for some children, death is realistically understood a good deal earlier than Nagy's work suggests. Spinetta and Deasy- Spinetta (1981) observed children between the ages of six and ten who understood the meaning of death. These children were cancer patients which led them to propose that the experience of living with a life-threatening disease may accelerate the process of understanding the finality of death. Bluebond-Langner (1978), working with terminally ill children, found that such children may feel that they will alienate people if they talk about death and therefore do not always share what they know. This withholding may lead to mistaken beliefs about the child's inability to understand death.

Children's Grief

A prominent theme that arises with regard to parental loss and more recently, sibling loss, is the question of children's capacity to mourn (Rosen 1986:3). Beginning with Freud's classic exposition of grief work in "Mourning and Melancholia" (Freud, 1917) and continuing through most of the literature on adult bereavement, the ability to express grief and sorrow following the loss of a loved one has been associated with coping and adaptation. According to Peretz, a psychologist, speaking of adult bereavement:

> If the lost loved or valued object was emotionally significant in the life of the bereaved, the absence of a grief reaction or symptoms of bereavement suggests a prognosis of future maladaption (Peretz, 1970:21).

In relation to bereaved children, it could be argued that the same could apply, not because children do not grieve, but that they have learnt to suppress emotions, as this is the model that has been learnt not only from their parents but also from society at large. Observation of bereaved children has led to contradictory conclusions. Speculations range from Bowlby's view (1960:481-498) that infants as young as six months experience mourning reactions identical to adults, to Wolfenstein's belief (1966:93) that the capacity to mourn is not acquired until adolescence. In between are psychologists and psychiatrists who believe that the ability to grieve is acquired sometime in childhood, as ego functions mature and/or the ability to comprehend the finality of death is achieved. Furman, a child psychiatrist (1964), places the capacity to mourn at around three and a half years, following the ability to comprehend death at approximately two and a half. He acknowledges that certain factors can also inhibit reactions at this age, making it appear as if the child cannot mourn. Anna Freud (1960) specified that in order for mourning to be possible, an individual must possess certain ego capacities, among them reality testing, acceptance of the reality principle, and control of id tendencies. These capacities have been assumed to be absent in the young child.

It would appear that the ability to comprehend the finality of death is essential to grieving, but it should be noted that even on this point there is no unanimity of opinion. Schell and Loder-McGough (1977), suggest, for instance, that it is not necessary for a child to have a realistic concept of death in order to grieve. They propose that in any case the child will react to the separation and that:

> after all..... the main thing to which we all react emotionally in a grief situation is the separation itself (Schell and Loder-McGough 1977:66).

The Reactions of Children to the Death of a Sibling

The investigation of children's reactions to the death of siblings remains in the early stages. Children's reactions to the loss of a sibling, as opposed to the loss of a parent, have received much less attention from those interested in childhood bereavement. The reason for this may lie in the fact that sibling relationships are considered secondary and relatively unimportant when compared to parent/child relationships. As Bank and Kahn suggest:

> We had been taught that siblings are, at best, minor actors on the stage of human development and their influence is supposed to be fleeting, and that it is the parents who principally determine one's identity. The prevailing theories of human development seemed strangely silent about siblings (Bank & Kahn, 1988:5).

However, although dated, Cain and Fast's study of 58 children aged between 2 years and 14 years, has shown clearly that:

> the primary if not exclusive pathological impact of a sibling's death upon the surviving child is one of guilt over rivalry-bred hostile wishes which, through the early impotence of thought, are seen as having been fulfilled by and responsible for the sibling's death (Cain and Fast, 1964:751).

In over half the cases they studied, they found that guilt was raw and directly present as was trembling and crying at the mention of the sibling's death, even five years after the event. The guilt was variously handled by each child in accord with his/her unique personality structure, with reactions including depressive withdrawal, accident-prone

behaviour, punishment seeking, constant provocative testing, exhibitionistic use of guilt and grief, massive projection of super ego accusations and many forms of acting out.

While sibling loss does not necessarily result in severe pathology, a wide range of disturbed reactions is possible (Pollock 1962). These include guilt reactions, death phobias, disturbances in cognitive functioning and distorted concepts of illness, death, doctors, hospitals and religion. More recently in Rosen and Cohen's study (1981) of 159 bereaved siblings, it was found that children also reported feeling sad and hurt, lonely, angry, confused, frightened, disbelieving, apathetic, and numb.

In Worden and Silverman's controlled study of 125 children in Boston whose parents had died (1996), they found that anxiety levels were higher for girls than boys and rose significantly for all children during the first year of loss. Anxiety was associated with more disruption of daily life and with feeling less in control. Health problems were more frequent in the bereaved group, girls experiencing more difficulties than boys. Worden (1996) suggests that overall the death of a sibling does not portend more emotional/ behavioural problems than the loss of a parent during the first year of bereavement. Approximately, one quarter of the children fall into the at risk group, regardless of the type of loss, during the first six months. Although a smaller percentage of families whose child died have children at risk, when they do, this risk is more likely to affect a greater number of children in that family.

This section has demonstrated that children may understand death from an early age, that children do grieve, and that the death of a sibling may have a profound effect on them.

As there may also be grandparents in a family where a child dies, this aspect will also be considered.

The Grief of Grand-parents

It is possible, because there is a paucity of research or writings on grandparents' grief, that the effects of a grandchild's death are often underestimated and undervalued. Ponzetti & Johnson (1991:63) consider bereaved grandparents as the "forgotten grievers": those grandparents who remain unsupported whilst they have given assistance to their grieving children. The untimeliness of a child death, reminds grandparents that as they are nearer the end of their life span, it is they, not the child, who should have died. This can cause painful guilt, as illustrated in the following quote:

> Guilty about what? Guilty that I am alive and my beautiful grandson is dead. Guilty because my daughter is torn apart by grief. Guilty because after he died, I sought help for myself. For the first time in my life, I put myself before anyone else. Why? Because I was in so much pain, I couldn't help anyone else (Hindmarch 1993:37).

In a small study of family support and bereavement, Kowalski (1987) interviewed grand-parents in five families. Perhaps not surprisingly, like parental grief, she found that grand-fathers were factual and unemotional and less involved, whereas the grand-mothers were more open in sharing their emotions. The maternal grand-mothers' primary concern was the welfare of their daughters, their own grief being secondary. Grand-parents regretted being unable to protect their children from grief, but failed to relate such feelings to the bereaved parents, as the reality of the dead baby was hard for them to accept. Kowalski, like Smialek 1978) also found that the grief of some grand-mothers related not to their present loss, but to earlier losses. Smialek argues that support should be provided for those who grieve regardless of the source of their grief, not assuming that their sorrow only relates to the current death.

The fact that there is little written on grandparents' grief would point to the fact that more research is needed to understand their particular pain, and also to consider what help they might need.

Summary

While the stage theories have helped us to understand the psychological effects on the bereaved, they do not include the physical or spiritual aspects. This chapter has shown that bereavement is an holistic experience affecting a grieving individual, not only psychologically, but also physically and spiritually. Whilst much of the earlier research was conducted on spousal grief, there is clear evidence to show that parents undergo a similar process, although the sudden, unexpected death of a child results in a longer period of intense shock and distress, requiring much energy in adapting to the loss. Parental guilt and helplessness is central to their grief. Mothers would appear to grieve more intensely and longer than fathers, although fathers tend to hide their feelings more and will grieve in private. Researchers advocate that the large proportion of mothers and fathers, indicating strong to severe reactions after the death of a child, should lead health care professionals to be sensitive to the presence of these reactions in order to facilitate care and support.

Whilst it is crucial to understand the grief experience of parents, children in a family where a sibling has died may also suffer profound grief reactions. It has also been shown that the grief of grandparents may go unnoticed. Thus it is demonstrated that grieving for the death of a child is a family affair, involving all close family members.

Having discussed what individuals in the grieving family may experience following the death of a child, the next chapter will consider inter-personal difficulties that may arise amongst family members, as the result of the death.

CHAPTER 4

THE INTER-PERSONAL ASPECTS OF BEREAVEMENT

Introduction

In the last chapter, individual reactions to a significant death, that is intra-personal effects, were discussed. But as bereavement is a family affair encompassing all members of the close family (Worden 1984; Stroebe, Stroebe & Hanssen 1993), it is also necessary to consider the effect on the family system, that is the inter-personal dimension. It has been suggested (Worden 1983) that family dynamics can hinder adequate grieving, and that families vary in their ability to express and tolerate feelings. Worden (1983) recognises three main areas to be considered in assessing grief and family systems: the functional role the deceased played in the family, the emotional integration of the family, and the way in which families facilitate or hinder emotional expression. Thus when a family experience bereavement, the reactions of each, and to each other are necessary when making assessment of needs and in helping to bring about resolution for the whole family. This chapter will explore three issues: firstly, it will consider research that has been conducted on the difficulties that parents may experience in their relationship with each other as a result of the death; secondly, the difficulties that may arise in surviving offspring that parents may have to deal with; and thirdly, the research that has been conducted on relationship difficulties that may arise with grandparents.

Bereavement as a Family Experience

Walrond-Skinner, a social worker and family therapist, has defined a family as:

> A dynamic, interdependent psychological unit, made up of individuals and the interactions between them, a nucleus of whom form a household over time and may be related by either blood or law in addition to their emotional bonds. Whilst a family will evolve and change throughout the course of its life-cycle, its members will retain crucial emotional significance for one another of both a positive and negative kind (Walrond-Skinner1988:11).

The family is considered a unit, and when this unit is disrupted by the death of one of its members, the breach is difficult to repair (Sanders 1989:151).

Throughout life, family dynamics are in constant flux and rules are always open to challenge, revision and reinterpretation. A family bereavement may result in changing existing rules which places an additional burden on surviving members, especially bereaved parents. Energy invested in grief will inevitably mean that energy for other areas will not be available (Sanders, 1989; Worden, 1983).

Following a loss, a family system is likely to operate conservatively, maintaining the system as it was before the loss (Rosenblatt, 1983). Family members may have differed in their relationship with the deceased and as a consequence will grieve differently (Lofland 1985). This may inhibit their ability to support one another. As a result, grief for the missing family member may be compounded by grieving for the system that now seems inadequate to meet the survivors' needs. While the change from intra-personal to inter-personal is a major change from the stage models, the process within a family is complicated further. Grief is a highly individualised process, with many and varied patterns when even one's individual grief varies from moment to moment (Shuchter and

Zisook, 1993). In the past, accounts of grief have frequently been overly simplistic, so that there is a need now to consider a multi-dimensional approach, one that incorporates overlapping dimensions, including affective states, coping strategies and the continuing relationship with the deceased (Shuchter and Zisook, 1993). As Bowen has suggested:

> Knowledge of the total family configuration.and the overall level of life adaptation are important for anyone who attempts to help a family after a death (Bowen, 1978:328).

The Relationship between Grieving Parents

The death of a child has a paradoxical effect on the relationship between the parents (Klass, 1987). The shared loss creates a new and very profound tie between them, yet at the same time the different feelings engendered by the loss, may create an estrangement in the relationship. The paradox is expressed differently in couples with different relationships before the death. This paradox plays itself out in different forms as the parents individually, and together, come to terms with the emotional and spiritual dimensions presented to them by the death of their child. But as Klass (1987) suggests, the paradox of a new bond amidst estrangement is a central theme in the marital relationships among bereaved parents.

In addition to the personal grief felt by each partner, anxiety about the other's style of grieving may further push the parental couple towards different cultural expectations (Helmrath & Steinitz, 1978). Like Verbrugge (1985), Riches & Dawson (1996:149) have highlighted that the grief "work" required in dealing with the death of a child, often produces a division of labour between the partners involved: the father copes through "doing", supporting his partner, being strong and "picking up the threads",

whereas mothers cope by not coping, weeping openly and expressing the pointlessness of living as a result of the death of their child.

However, as Osterweiss, Solomon and Green (1984) suggest, "synchronicity" may be a problem for parents following the death of their child. As was noted in the previous chapter, fathers may adjust to the loss more quickly than mothers which may result in misunderstandings and tension between the couples. Clyman et al (1980) reported that the fathers in their study expressed a desire to move on with life, while the mothers remained depressed and preoccupied with thoughts of the dead child.

Worden (1983) suggests a series of steps for the bereaved to take in relation to recovery. He sees recovery being achieved through a series of tasks. His four tasks are defined as: acknowledging the reality of the loss, experiencing the pain of grief, adjusting to a new environment without the deceased and reinvesting in other relationships. However, the importance of "grief work" has been questioned. Wortman, Silver & Kessler (1993) suggest that this may not be the case. They consider the work of Parkes & Weiss (1983) who looked at the degree of yearning in those recently bereaved, finding that high yearning was a predictor of poor mental and physical health outcome at 13 months post death, and also at two to four years after the loss. Silverman & Wortman (1986) considered parents who had suffered a cot death, finding that the more parents were "working through" the death at the 3 week interview, the more distressed they were 18 months later. In addition, those subjects who showed the least evidence of emotional resolution 18 months after the death (measured by distress in thinking and talking of the baby, feeling bitterness about the loss and being upset by reminders of the baby) were

those most likely to be processing the loss after the death. They challenge the assumption that the absence of "working through" leads to complications later. They do not accept that "working through" the loss will necessary achieve a state of resolution. In their cot death study (1986), parents, at 18 months were still asking "Why me?" or "Why my baby?" which they considered a sign of non-resolution. In the case of death from motor vehicle accidents, Lehman et al (1987) found that 39 spouses and 54 parents, 4 to 7 years after the death, had not achieved resolution. They conclude that contrary to popular belief, individuals are not always able to achieve resolution and to come up with an explanation which is satisfactory to them. Particularly when the event is sudden, and unexpected, a majority appear to have difficulty in coming to terms with what has happened. However there is no mention in any of the studies as to whether these families were receiving support after the death, and whether, if this was the case, it made any difference to their outcome. Sudden death, especially that of a child has been identified as putting the bereaved more at risk of having a more complicated bereavement pattern (Parkes, 1972; Raphael, 1984; Rando, 1984), but in their studies, there is little mention of any comparison in outcome between those who may have received support with those who may not. It is assumed that all who experience a sudden death will be likely to have complications. It would be useful, therefore to conduct further research into two different groups, those receiving support and those who do not, with the aim of establishing if all have a more difficult bereavement.

Similar to Wortman & Silver (1986) Stroebe, (1993) a Dutch psychologist, also questioned the long-standing belief in the importance of "grief work." She sees little empirical evidence to show that doing "grief work" is of benefit to all bereaved. Using

the models of other cultures she demonstrates that some cultural norms dictate that the bereaved should avoid all reminders of the deceased; in others a persisting reverence of a deceased family member is accorded. People in the former culture would seem to cope with their bereavement as well as those in the latter.

Her model differs from the grief work model in that it rejects that there is a normal or standard process of coping with grief. She uses the field of personality which shows that there are systematic individual differences in styles of coping. Using the data from her longitudinal study in Holland (1992), she found that of 60 bereaved spouses, some (n=43) preferred to confront, others to repress loss and yet engaging in grief work made no difference to their coping. Widowers who tended to repress feelings by keeping a "stiff upper lip" had trouble in adapting to their new role, whereas those who ignored role expectations and who confronted their loss were helped by grief work. Thus she argues that for some, grief work will be useful and helpful; but for others, whose style of coping is to suppress painful memories and distract themselves with other activities, it will be of little value, and recovery will eventually ensue without engaging in it. This would seem particularly relevant to a bereaved couple who may have different coping styles.

Stroebe's dual process model (1993) considers not only the loss of a significant person but the losses which arise as the result of the death. She believes also that time away from grieving from one or both is necessary. Her model considers two main concepts: loss-versus restoration-orientation and approach-avoidance dimension

The Dual Process Model

Loss-versus restoration-orientation

Orientation means that a person is concentrating on, dealing with and processing some aspect of the loss experience which falls within the grief work concept. On the other hand, restoration-orientation means coping with substantial changes that are secondary to the loss, such as practical arrangements arising from the loss, the development of a new identity (for example, from parent, to parent of a deceased child). Loss-and restoration-orientated coping is a dual process because both dimensions require working through, but cannot be attended to simultaneously, although attention to one will bring reminders of the other, thus producing "oscillation." This model can therefore be used in the context of different cultures where the dual processing is conducive to adjustment. It would also seem appropriate where two bereaved parents and others in the family are grieving.

The approach-avoidance dimension

This applies to both loss and restoration and is also a dual process. Some people will adopt a way of coping by confronting the loss experience whereas others will avoid discussion, distract themselves and keep busy. In Western society, there is clear evidence of using both coping styles. As was seen earlier in this chapter, mothers tend to confront whereas fathers tend to distract themselves. Stroebe (1993) suggests that rather than stressing the necessity of grief work, there is a need for balance between the tasks of coping, an oscillation between approaching and avoiding loss and restoration with necessity to rest from confrontation of the loss experience with time not to cope at all. Stroebe has highlighted the need to both approach and avoid loss so that the tasks of

grieving over the loved one are attended to as well as the secondary losses which can be sources of additional stress. In addition, she advocates the need to take time off completely from either coping orientation. She uses Worden's Task Model (1983) to show the dual tasks, as shown in Table 2.

Table 2 Differences in Grieving Tasks

Worden	Stroebe
To accept the reality of the loss	To accept the reality of the changed world
To experience the pain of grief	To take time off from the pain of grief
To adjust to an environment in which the deceased is missing	To change/master the subjective environment in which the deceased is missing
To relocate the deceased emotionally and move on with life	To develop new roles, identities and relationships

Therefore in the context of a bereaved couple, Stroebe's model helps us to understand that each parent will have to deal with both the primary and secondary losses that arise from the death of a child, and may do so in different ways at different times. This would seem to reinforce Osterweiss, Solomon & Green's suggestion (1984) that synchronicity may cause problems.

Marital communication and problems associated with it are frequently reported. Kaplan (1976), reinforced by Lauer at al (1983) suggest that between half and 70% of parents whose child dies of cancer will experience a marital breakdown. In Cornwell et al's sample of couples whose children were still-born (1977), well over a third experienced marital problems. Kalnin (1980) also reports marital problems in nearly three quarters of his sample of parents whose children died of leukaemia.

However, in Dyregrov and Matthieson's sample of 55 couples (1987), over a third said that talking together about their child's death brought them closer together. Sharing painful feelings was felt to be a key factor in the resolution of both parents' grief. However, mothers felt there was a difficulty in keeping the child's life "real", especially when others wanted to change the subject. On the other hand, fathers' grief was frequently overlooked because of their inability to talk of the child's death (Littlewood & Cramer, 1991).

The Parent/Child Relationship

Only occasionally has sibling loss been examined in the context of the family (Rosen 1986). The death of a child can significantly disrupt the structure and organisation of the family, and parental grief and mourning can hinder surviving siblings in their efforts to adapt (Cain, Fast & Erickson, 1964:741-752). Whilst bereaved parents are faced with their own grief and pain, and adjusting to a changed relationship with each other, where there are surviving children, they also have the burden of trying to support them. Siblings may desperately seek reassurance and strength from their parents, who, because of their own pain and normal loss of functioning, find it difficult to offer help (Sanders, 1989:151). Generally adults occupy more central positions in the family than children and therefore will influence ways of communicating and reacting. How a child reacts to various losses will depend much on how they were dealt with by significant people, especially their parents (Rosenblatt, 1993). Reinhold believes that early life experiences mould adult responses.

> We've slowly come to recognise that the experiences of childhood influence the ways in which we feel, think, act and respond through our lives. The events,

> circumstances and relationships of our early past have a profound and implacable effect on our adult lives (Reinhold, 1990:3).

Therefore it follows that the way in which children are helped through a major bereavement is vital to their future development and adult understanding of loss.

The inter-personal approach therefore does not replace the intra-personal one, but highlights the need to work within the dynamics of a family as well as being aware of the unique response of an individual.

It has been assumed that children are unable to express themselves as directly and fluently as adults, and therefore cannot talk about their feelings and attitudes concerning death (Rosen, 1986). However, children are able to talk of feelings if they are given permission to do so. The key to understanding children may lie in careful listening and picking up cues that a child gives. Sometimes the questions a child asks may entrap the person who fails to understand where the child's line of questioning is going (Jackson, 1984). Gorer (1965) points out that many adults ignore the questions asked with the implication that the questions are improper or inappropriate. Some adults admit that they give answers that they do not believe but cannot think of anything else to say. As a result, children may lose confidence in the adults to whom the questions are directed and are denied a working understanding of life crises. Invariably they will go elsewhere, only to find a similar approach. The breakdown in communication also tends to be projected into the future with the feeling that, if there are important answers to be sought, they cannot be found with certain adults, who are obviously threatened (Jackson, (1984).

In Cain and Fast's study (1964), they found that parents clearly would not allow the remaining sibling to talk of the event. The parents rushed in with heavy repeated reassurances, quickly labelled it all an accident and cut off any possibility of the child's telling what (s)he felt had happened. Parents had been led to believe that allowing the child to talk of the incident would only cause upset and make it linger in everyone's minds. In nearly one quarter of the cases, they found that guilt regarding the sibling's death was essentially imposed by the parents, but not by blaming the child for the sibling death. Rather it was, that the child had shown no regret, no sadness, no grief at the loss of the sibling. Cain and Fast (1964) concluded that there are many variables which affect a child's grieving pattern including the type of death, the age and characteristics of the child who died, the child's degree of actual involvement in the sibling's death, and the child's pre-existing relationship to the dead sibling. Siblings were also affected by their cognitive capacity to understand death, the immediate impact of the death on their parents, and the way in which parents managed the initial reactions of the surviving children. The impact of death on the family structure and the parents' enduring reactions to their child's death also played an important part. The reactions of the community, availability to the child and the parents of various substitutes, and concurrent stresses upon the child and family also contributed. The majority (62%) of these children had shared their reactions with no-one. Many of these siblings felt a responsibility or need to comfort one or both parents, this feeling taking precedence over the need to express their own feelings of loss, coupled with a sense of having to make up to their parents for the loss. Care is more likely to focus on the parents, and on occasions older siblings are even expected to provide support for their parents (Rosen,

1984; Sarnoff Schiff, 1977). Rosen gives an example of a 12 year old girl whose brother had died after being struck by a truck:

> I was very worried about how my parents were feeling and felt that if I ever let all my sadness and grief show, it would make things worse for them. I never talked to them about my feelings (Rosen 1986:17).

Sarnoff Schiff (1977) also found in her discussion with surviving siblings, many years after the death, that little help or comfort had been given by their parents when their sibling had died. One woman who was interviewed commented:

> I kept looking for some help from my mother after my brother died. Although he died when I was sixteen, I'll never forget that feeling of aloneness, or how frightened I was, because neither my mother nor father seemed reachable. I really don't remember them trying very hard to help me. They were too busy with their own grief (Sarnoff Shiff,1977: 69).

A similar comment was made by another woman whose sibling had died when she was a child:

> I felt like I had been pushed aside and I used to cry in my bedroom. I wanted to be talked to as a person, but instead I felt like a burden every time I tried to speak to my parents about Robby. The thing I wanted most was my parents' time so we could talk, but that rarely happened. Instead, our house seemed like it was always filled with people (Sarnoff Shiff, 1977:71).

Rosen (1986) observed that in examining patterns of communication and adaptation, in some families there was a high risk for the development of pathology because parents were unable to recover from the loss. In these circumstances, the family life cycle became frozen, and there was an inability to nurture surviving siblings. These were the families in which the loss of a child bred pathology for the future of the entire family. There is, therefore, in the light of these findings, a real need to identify such families so that help can be given where necessary.

For instance, Krell and Rabkin (1979:471-477) have described three types of survivor children, based on family dynamics and reactions to the loss. They identified the "haunted child", the "bound child" and the "resurrected child". The haunted child is distrustful and fearful because of silence in the family surrounding the circumstances of the death. The bound child is overprotected as a result of the family's attempt to prevent further catastrophe. The resurrected child is the surviving child or new infant who has become a replacement for the child who died.

The death of a sibling does not necessarily impose the same survival issues that are present when an adult dies, as there may be fewer changes in the child's life- style. However, Bank and Kahn (1982) have proposed eight patterns of sibling identification that accompany the most common sibling reactions. At one end are "fused" relationships, where siblings lack differentiation from one another, each feeling like an extension of the other's self. At the other end are negative and distant relationships where anger, hostility and rigid differentiation predominate. In partial identification, there is a positive and flexible sense of sameness and difference. They suggest that when a child dies who was at either end of the spectrum, there is a profound potential for pathology to develop in the surviving sibling.

When a parent dies, a child is generally perceived to have suffered an important loss, and so those around tend to accommodate the child's needs with more sensitivity (Rosen 1986). With parental and sibling loss, a child may experience a range of emotions which include anger, guilt, grief and abandonment. The child may attempt to deal with these powerful feelings through denial or suppression. As Blinder (1972) suggests reactive

disorders in children occur primarily when the bereavement process for the dead child has been truncated.

The Influence of the Family

Raphael (1984:115-119) has outlined seven different ways that families where there are surviving offspring, may deal with the death: the family where death is a taboo, so that death is never discussed, and therefore children are not included in rituals or able to ask questions about the death; the family in which someone must be to blame for the death, where guilt is a powerful force used in socialising the children and punishment takes the form of covert or overt interactions designed to increase the bad feeling; the family in which close relationships are avoided, where the emotional "tone" of the family is "cool", so that whilst some distress is shown initially at the death, feelings are rapidly covered up. A child may be bewildered by the intensity of his/her feelings and by the lack of distress shown by the parents but (s)he learns to keep feelings low profile because the parents cannot tolerate them. (S)he learns also to be "cool;" the family in which things must go on as before, where feelings are not faced, because the loss or absence is not really acknowledged within the family system. A child is given the clear message that his/her only chance for safety and survival lies in fitting in; the family for whom the death means chaos, where it is likely that chaos has been the dominant feature in the family before the death. Such families may have little financial or personal resources and may already be known to welfare services. A child in such a situation is likely to also be in chaos; the family that must do the right thing, where parents endeavour to learn the right thing to say and do. A child learns a pattern of response that is fairly adaptive but more covert messages may be picked up, in that the death was a

terrible thing that is neither understandable nor controllable; and finally, the family that functions with openness and sharing of feelings. A child will suffer pain, but he is helped to master the loss by care and consolation of others, so that healing may take place.

It is obvious from Raphael's description of family themes that parents' role in the grieving pattern of their surviving children is vital. Some families will require sensitive help and guidance; other families will require little help, although they may appreciate encouragement and affirmation of what they are doing is right. There is a wide variation among families in their ability to cope. Specifically three types of family have been identified in this regard (Rosen, 1986:79): families in which there is a cohesive cultural sub-group, where family and friends aid each other and meet the needs of the bereaved family members, isolated families, atomised and nuclear with limited social contacts, and atomised nuclear families who may depend on professionals to guide and support them. Family intervention at the time of the loss may be most useful in assisting the family with the coping and adaptational tasks it faces. For surviving siblings, it may also open the door to family acknowledgement of their grief and the need to mourn (Rosen, 1986).

As Dyregrov (1991:55) suggests, perhaps the most important help that parents can give their children, is to care adequately for themselves, so that their reluctance to confront what has happened, does not impede the child's grief work. It is therefore important for parents to ensure their own working through of what has taken place. He also suggests that to be able to meet children's needs, it is necessary for them to acquire information

about children's reactions, be prepared for their questions, and to get advice on how best to help them.

However, where do parents go for such guidance, and how do they know in the first instance, that they may need help? This would seem to be a role that professionals already known to them could fulfil.

It would appear that even over thirty years later, Cain's remark is still relevant:

> A full preventive- therapeutic approach to the dead child's siblings, integrated with assistance to the grieving parents, remains to be carefully spelled out. But recognition of the need for such efforts represents a major step toward preventing what we elsewhere called the senseless arithmetic of adding newly warped lives to the one already tragically ended (Cain, 1964:752).

Having considered the different difficulties that may arise where there are grieving children, the last section in this chapter looks at bereaved grandparents in terms of their relationships with the bereaved parents and other children.

The Parent/Grandparent Relationship

For grandparents, their grandchildren represent a continuing link with the future at a time when they are more than ever thinking of their own mortality. Being grand-parents gives them a further opportunity for enjoying children, watching them grow and develop, probably with more tolerance than with their own children. Marris (1982:75-98) observed that children's ability to create conditions for mature adult attachments depended upon several early nurturing figures who loved them. It is the emotional attachment between grandparent and grandchild which is unique as it displays an

unconditional love given by the senior (Burns & Madian, 1992). Miller & Cavanaugh, (1990) outlined five aspects of grand-parenthood: centrality, valued elder, immortality through clan, re-involvement with personal past, and indulgence. However, they suggest that not all grandparents see the salience of their role or are given an opportunity to engage in it.

The sudden death of a child is a family crisis. Unless the family system is flexible in its capacity to express feelings of sadness, anger, and guilt, it may have difficulty in adapting to such a tragedy. Such difficulties may extend into other generations where grandparents may be used as scapegoats (Raphael, 1984). Walter (1994:16) suggests that as norms for death are changing, so different generations may no longer know how to communicate with each other about the death. For instance, a traditionally religious grandparent, a stiff upper lip parent and an adult child who has learnt to be more expressive may have great difficulties in communicating at precisely the moment they need to most. Although there is no reference in the literature, I have found in my own practice that grandparents, because they were brought up in a different generation may believe that children in the family should be protected from the details of the death, any ritual surrounding it, and may be of the belief that children do not grieve and will not understand about death. This may conflict with the parents beliefs which may in turn cause family difficulties.

Grandparents may have a personal emotional investment in the grand-child who has died and may consider one of the parents responsible for this blow to the on-going family of posterity. Their grief is not often recognised, and their critical role in the

adjustment of young parents who turn to them for support, may be ignored (Raphael, 1984). Some grandparents will have been directly involved with the care of the child who has died, where the intensity of their grief will be similar to that of the parents. Not only are they coping with their own pain, but that of their child's. Some mothers, therefore, may be disappointed in their own mothers for their failure to understand and offer emotional assistance (Raphael, 1984:274). As one grand-mother commented:

> Other people feel I shouldn't be grieving the way I am, because it was only my grandson. We weren't just nanna and grandson, we were friends. I am grieving not only for him but for my daughter as well. I found I couldn't help her (Hindmarch, 1993:37).

As was stated in the last chapter, we have little understanding of the difficulties that might arise between parents and grandparents. The paucity of literature would suggest that this is an area for future exploration.

Summary

This chapter has considered the literature on the inter-personal aspects of a family who have experienced the death of a child. It has been demonstrated that differences between the patterns of grieving between mothers and fathers could lead to misunderstanding and tensions between the couple. It has also been shown that parents have a key role, where possible, in helping their children through grief, but may have difficulty in doing so because of their own pain, diminished functioning that the death has produced, lack of knowledge on children's grief and few resources to turn to for guidance. Different family responses have been demonstrated which may hinder or help a bereaved child. The literature on grandparents is extremely limited but what is available shows that

grandparents, whilst having their own grief to deal with, may prevent them from helping their adult children. The generation gap may cause difficulties with communication and beliefs particularly where there are other children in the family.

It would seem, therefore, that the death of a child affects all in the close family, not only individually as was demonstrated in the last chapter, but also in the relationships with each other.

Chapters 3 and 4 have considered the intra and inter-personal aspects that may arise as a result of a child's death. The following chapter will look at a third dimension, that of the extra-personal which involves the attitude and support of those from outside the close family.

CHAPTER 5

THE EXTRA-PERSONAL ASPECTS OF BEREAVEMENT

Introduction

It was shown in the last two chapters that the death of a child has the potential to affect all in the close family, thus each member will experience their own personal reactions as well as being influenced or affected by the grief of others in the close family. The need to view a bereaved family both intra-personally and inter-personally is now recognised (Worden, 1983). However, within that close family group, there may be other stresses which hinder or help the grieving process, that of external influences. This extra-personal aspect includes the attitude and support from less close family members, neighbours, friends and professionals, which may give rise to further stress.

The aims of this chapter are to explore what is meant by social support, what functions it has, and to what extent support structures are available for families where a child has died.

Social Support

In its broadest sense, social support may be defined as the resources provided by other people (Cohen & Syme, 1985). Social support networks, that is the extent of a person's relationships with other people, are believed to play an important role in the amelioration of the stresses associated with the impact of various life events (Littlewood, 1992). A key distinction has been made between structural and functional aspects of support. Structural indicators consider the existence or number of people in an individual's social network whereas functional measures focus on the actual provision of support from people. Henderson, Byrne and Duncan-Jones (1981), for

example, compared the availability and adequacy of support, while Lin, Dean and Ensel (1986) distinguished actual from perceived support. A large social network suggests, but does not necessarily demonstrate, that support is adequate, whereas for some, a small social network can, in fact, provide sufficient support. However, Alloway and Bebbington (1987:94), posit that there is no generally accepted measure of social support and that most researchers have simply devised questions of their own. These have been based on common sense and face validity rather than on empirical or theoretical underpinnings (Sarason, Sarason and Pierce, 1990).

Whilst Chesler and Barbarin (1984) conducted a study on parents whose children died of cancer, Thuen (1997) suggests that the four difficulties they identified, could also relate to other bereaved parents. These are: parents' concerns about the emotional impact on both their family and friends, other people's concerns about how attempts to help might compromise privacy and alter friendship, parents' concerns about the stigma of needing help, and parents' and others' concerns about overcoming traditional sex-role barriers to giving and receiving help.

The Function of Social Support

Social support serves a variety of functions. It may be important to have particular types of support during certain life events. Cohen & McKay (1984) have hypothesised, for example, that bereavement and other disruptions of close interpersonal relationships create a need for support mechanisms they call "belonging," where close, relatively intimate relationships will be most effective in meeting this need. Rook (1987) has found that those exposed to major life events require help from others, or social support and companionship, that is, social exchanges providing recreation, humour, and affection which contribute to a sense of well-being. Whereas support may protect people from the debilitating effects of life stress, companionship protects them from the

emptiness and despair associated with loneliness (Rook, 1987). Stylianos and Vachon (1993) suggest that social support also provides a mechanism for social comparison. In the absence of objective criteria or when faced with new experiences, people tend to compare themselves with others or individuals in similar circumstances in order to evaluate their behaviour or feelings (Festinger, 1954). Self-help groups, for example, may provide people with the opportunity for social comparison. The possibility for social comparison is also enhanced by a homogenous social network where there is increased likelihood that another member will have had a similar experience (Walker et al, 1977).

Social support has been linked with better mental health (Cohen and Willis, 1985; Kessler, Price and Wortman, 1985; Alloway and Bebbington, 1987; Sarason, Sarason and Pierce, 1990), and the extent to which parents receive social support in bereavement is generally found to be related to the psychological adaptation process (Helmrath and Steinitz, 1978; Jurk et al, 1981; Nicol et al, 1986; Tudehope et al., 1986). Thus, where support is lacking it could be assumed that bereaved parents are more likely to develop poor health, both physical and mental.

The Stress-buffering model

Researchers have suggested that a person's social support system may help to decrease or buffer the effects of stressful life events on psychological well-being (Cohen & Wills, 1985; Kessler, Price & Wortman, 1985; Thoits, 1982). Evidence from survivors of natural disasters and holocausts caused by human agency would indicate that, when stress is sufficiently prolonged and severe, nearly all involved are likely to display psychiatric symptoms. Consequently, professional provision of support to "buffer" the impact might be expected to be particularly important (Dohrenwend,1975). Barrera has suggested that part of the popularity of the stress- buffering model lies in the recognition

that:

> the occurrence of many major life events could not be prevented, but social support could mitigate adverse reactions to such events (Barrera, 1988:229).

Cassel (1976) considers the stress buffering model to be particularly important since it is easier to provide interventions to strengthen social support than to reduce stressors. Thoits (1982) also attributes importance to the development of the model because social relationships may be more amenable to change than personality or preferred coping mechanisms. However, bereavement is a social network crisis, especially after the death of a child, when the joint experience of suffering may render those outside the close family network unable to support the bereaved family. For this reason the support of outsiders, such as professionals, may alleviate the situation.

Stress Prevention Model

This model was designed to demonstrate the ways in which social support might have a direct influence on the prevention or reduction of distress (Gottlieb, 1981; Gore 1981). Such a model suggests that stress processes can be altered by social support. The main concepts suggest that supportive exchanges which give information, and give behavioural guidance may avert or stop consequences of stress. Secondly availability of this type of support for the bereaved person may change the perception of the stress value of the life event and its consequences. Controlled studies (Parkes, 1980; Raphael, 1984) have shown that this model of intervention can reduce later distress and morbidity. Parkes (1980) found that those bereaved who had received social support from either professional or self-help services, had a reduced risk of post-bereavement morbidity. Raphael (1984) studied the effectiveness of an intervention programme in improving the health status of widows. The treatment group was found to have a better outcome at thirteen months than the control group. She sees, like Parkes, that the provision of support plays an important part in minimising post-bereavement morbidity.

Edelstein (1984) investigated the social support available to mothers after the death of their child. She ascertained that while most of the mothers in her study used support from professional sources, very few of them actually sought it out. Most of the mothers perceived doctors or the clergy as possible sources of support, but their assessment of the value of help was extremely ambivalent. Doctors were perceived as not doing their job properly, and the clergy criticised for not knowing their child, and "not understanding death." The relationships that were most often maintained were those that had been established before the death. The mothers wanted someone to be there to listen and to understand.

Littlewood's study (1990) was concerned with parents' evaluations of the support received from hospital staff after a child's death from cancer. It was found that parents felt the support was good or very good. However, it could be argued that the staff were already known to the parents before the death, during the illness, and the child was also known by the staff; so professional support was perceived to be valuable only if it represented a continuation of support from professional sources prior to the death. In an earlier study, Littlewood (1983) found that the provision of a framework which informed and guided people concerning the appropriate steps to take after the death, was particularly highly valued. Many people reported feeling a need for help in bereavement but did not see professionals as a possible source. The main reason for this would seem to be a confusion over the status of bereavement itself. Many people would appear to see their responses to bereavement as inevitable, and so consider that little can be done to help them. Also the lack of available services to help the bereaved may be a deterrent for people in seeking help. Littlewood (1993) identifies four main reasons for bereaved people wanting help: fear concerning the experiences associated with grief, distressing interactions with friends and relatives following the death, loneliness as a result of the death, and ensuing depression. In considering perceptions of support received from

various sources following the death of a husband, wife, brother, sister, child or parent, Littlewood (1983) found that in relation to professional help, three main areas were seen as valuable: practical help immediately after the death, continuation of emotional support from valued professionals involved prior to the death, and a need for support from professional sources together with a recognition of its availability or unavailability. She sees provision of more informational support, and more focused supportive help from caring agencies, meeting some of these needs. However such support is not widely available or known, so that the bereaved are forced to fall back on friends and family for support which may be unavailable.

The Direct Effects Model

Such a model depicts a negative relationship between social support and distress, independent of any life stressor, and has as its main concept the fact that people have a basic need for attachment to others. Social support contributes to psychological well-being on an ongoing basis to reduce distress through contact. Bowlby's work on attachment (1969) is such an example. Barrera's work (1986) suggests that social support network size and social participation are more likely, in general, to conform to a direct effect than a buffering model. Cohen & Wills (1985) also suggest that structural measures of support are likely to show direct effects rather than interaction effects.

The Social Support Deterioration Model

Avoidance by others of the bereaved, thus reducing social support, would seem to be a problem associated with bereavement. Lehman et al (1986) have considered some of the mechanisms which might underlie avoidance or shunning. They found that, whilst possible supporters knew what kind of behaviours and patterns of communication would be helpful to the bereaved, they were unable, in practice, to be helpful. This, they suggest, arises from anxiety and uncertainty, which causes onlookers to fall back on

previously conditioned responses, such as, "you will soon get over it ", or "you can always have another baby." As a result, more traumatic deaths may arouse greater anxiety, so that forthcoming support is more likely to be absent. In Sanders study (1981) parental bereavement produced the greatest feelings of isolation and stigma. Parents were aware of the fact that what they had experienced was the worst thing that could have happened to them and that few individuals would want to connect with anyone who had experienced such a tragedy for fear of being contaminated.

It could also be suggested that for those on the periphery of a bereaved family, there is the added difficulty of not knowing how distressed the bereaved will be, and the uncertainty of knowing how they, the onlookers will cope with severe emotion, either their own or the mourner's (Lehman et al, 1986). People may feel unsure as to whether it is appropriate to offer support, for fear of being perceived as being invasive. Therefore, it would seem possible that many bereaved people must experience a need for social support, which is unlikely to be met from informal sources. Professional interventions in such cases may serve to buffer or prevent increased stress.

Although social support systems are potentially helpful, they can also be a source of stress (Gottlieb, 1983; Wortman & Silver, 1989). The social support system may behave in a negative way, especially if those affected by a death are not adjusting as others would expect. Shinn et al (1984) have emphasised that negative interactions that derive from supportive efforts are actually additional stressors and not just lack of support. Such negative stresses may increase the effects of other stressors.

The finding that the single best predictor of high distress one month after a spousal bereavement was a lack of contact with old friends, underscores the importance of network support in the days following death (Vachon, 1979). Several researchers have

found in spousal grief that a deficit in social support has been associated with poor outcome in bereavement as measured by poor health in the year following the death (Maddison and Walker, 1967; Maddison, Viola and Walker, 1969; Raphael, 1984). In relation to bereaved parents, the extent to which they received social support has also been linked to the psychological adaptation process (Helmrath & Steinitz, 1978; Jurk et al, 1981; Nicol et al, 1986; Tudehope et al, 1986). Therefore, as bereaved parents are frequently avoided by friends and associates (Brabant et al., 1995; Worden, 1991), or well meant attempts to support may have been seen as unhelpful (Lehman et al, 1986), the adaptation process may be prolonged.

During a bereavement period, social support may have diminished for several reasons (Sanders, 1989). Friends allot less time and energy to continue support after the funeral. They may expect the bereaved to have recovered from their grief in six months to a year, rather than in years. Generally, society has not been educated to acknowledge the length of time for recovery, contributing further distress to the bereaved who feel they should have been "back to normal" much sooner (Raphael, 1984).

Each individual will interpret support differently. The type, source and structure may seem more important than the amount of support received. House (1981), for instance, identified four different supportive behaviours: emotional support which involves care, trust and empathy, instrumental support which includes practical help, information support about relevant matters, and appraisal support which helps people to evaluate their performance, encouraging them to undertake various tasks. However, pre-existing psychological disturbances may determine both the perceived support and the subjective experience of major events. For support to be effective, it may only be relevant for certain types of events, and must match the needs of the life event. Several researchers have posited that social support is a transactional process requiring, for its optimal

provision, a fit between the donor, the recipient and the particular circumstances (Heller & Swindle, 1983; Shinn, Lehman, & Wong, 1984). Ben-Sira (1985) suggests that if internal resources of an individual are inadequate (innate traits, previous experiences, cultural characteristics and education), then external resources such as support may become more important. Introverts may draw into themselves, and extroverts may be more outgoing; but it does not necessarily follow that extroverts will have a better social network.

Whilst it is possible that feeling unsupported may lead to distress, it is also feasible that the perception of lack of social support may be the result of mental health problems. For example, individuals who are distressed, may simply see their support as negative or high levels of stress may lead to the rejection of supportive efforts or to the alienation of potential helpers who may be unwilling or ill-equipped to provide the amount of support required (Littlewood, 1992).

The availability, or otherwise, of social support following a death has been identified by researchers as being extremely important to the outcome of the bereavement process (Parkes, 1972; Worden, 1984; Stroebe, 1993). As Sanders has suggested (1989), feeling isolated and alone is a basic characteristic of every loss experienced. Problems arise, however, when a support system is actually lacking or if the bereaved individual permanently withdraws from others. Maddison and Walker (1967) showed that widows who were most open to risk, perceived themselves as having more unmet needs in interpersonal relationships than did those with good outcome. The widows felt they were not given an opportunity to express their grief emotions, especially anger and guilt. They also felt they were side-lined when they wanted to talk of their spouse. These findings have been endorsed by other researchers (Lopata, 1979; Raphael, 1977; Vachon et al, 1982a; Sanders, 1981). In the Tubingen study (Stroebe, Stroebe & Dormittner

1985) measures were included which examined both perceived social support and actual social network. The findings indicated that it was not so much the number of individuals available, but the quality of good dependable friends who can be called upon.

The bereavement literature has shown clearly that social support is an important factor. Where this is not provided, what other sources can bereaved parents draw on?

Available Support for Bereaved Parents

Support from the Voluntary Sector

Although not every bereaved person needs professional intervention, everyone needs support and social contact as they deal with the frightening aspects of grief (Sanders 1989:219). Social support can help to rebuild the person again. As Klein stated as early as 1940:

> If the mourner has people whom he loves and who share his grief, and if he can accept their sympathy, the restoration of the harmony of his inner world is promoted and his fears and distress are more quickly reduced (Klein,1940:329).

Because of social changes, and society's changed attitudes to death, discussed in Chapter Two, it may be difficult for the bereaved to share their pain. In the absence of help from other sources, bereavement agencies and self help groups have developed in the U.K. over the last twenty five years.

CRUSE was originally set up to help widows but now encompasses any type of bereavement, using trained and supervised counsellors. There are nearly two hundred branches throughout Britain. The Foundation for the Study of Infant Deaths funds research into cot death and offers support groups and befriending (as opposed to counselling) to bereaved parents in most health districts of England & Wales. Nearly all branches are run by bereaved parents (approximately 600), all of whom must have been

bereaved at least two years before they take on the helper role. The Stillbirth and Neonatal Death Society (SANDS) helps those who have suffered the death of their baby around birth. Nationally there are around 240 groups who offer befriending and self-help groups. The Compassionate Friends consists of 200 volunteers, all bereaved parents. They offer befriending specifically to other newly bereaved parents.

In recent years, the advent of bereavement centres for those affected by the death of a child has increased. The Alder Centre in Liverpool was set up in 1987 with the main aim of supporting all those in the area affected by the death of a child, of whatever age and from whatever cause. The secondary aim was to raise awareness about the needs of bereaved families. The operation was a partnership between parents and professionals in a non-medical setting and with open access. Similar centres are now run in Birmingham, Gloucester, Glasgow, Leicester, and Bristol, although Liverpool is the only centre funded by the local Health Authority, others being funded from charitable sources.

The National Child Death Help-line, supported by the hospital trust, was set up in 1993 at Great Ormond Street Hospital for those whose child has died within the London area. In 1995, the service became national, linking up with the Alder Centre in Liverpool. Together, the two centres offer a free phone service nationally to anyone affected by the death of a child. The service is manned by 80 volunteers, 40 in London and 40 in Liverpool. It is interesting to note that after the Dunblane massacre, the service was inundated by callers, not from those whose children had died in Dunblane, but from people who had lost children in other ways, some many years previously. This would indicate that the tragedy in Dunblane gave permission for other bereaved people to acknowledge their grief, finding an outlet in talking about it to caring strangers.

It would appear that because of the increasing proliferation of bereavement services,

there is an increasing awareness of the need to help families whose children die. Whilst the majority of the national bereavement agencies were started by lay bereaved parents, it would appear that there is now a strong move to organise themselves in a professional manner, by considering training, selection and supervision. The bereavement centres on the other hand, were all started by health care professionals who saw the need to provide a service to bereaved families, using trained volunteers, many of them previously bereaved, to help others. Such professionals have seen the importance of providing training, supervision and selection, all of which are vital in providing a good service.

Klass (1982) has suggested that the support received from those who have experienced similar tragedies, may be more helpful than professional intervention. However, Kalish (1985) is more cautious in advocating self-help groups, especially in the leadership of any such group, where sensitive handling is essential, but not necessarily assured. The professionalism of the voluntary agencies was questioned by Riesmann (1965), Brager (1965) Mantell (1983) and Davis & Fallowfield (1991), particularly in relation to use of volunteers who they considered were unsuitable. They also questioned their training, supervision, and the process of selection and accountability. Unfortunately there is little empirical evidence to refute this or back it up. While bereavement agencies appear to provide a need, the paucity of empirical research means that we have no means of evaluating their efficacy, what knowledge we have being, purely anecdotal.

However, Parkes, in considering the role of volunteers, believes they make an important contribution:

> Volunteers who have been carefully selected and trained to act as counsellors, or whose own experience of the transition in question provides them with inside knowledge, are often the best people to help others in transition. Not only are they less expensive but they are seen as less threatening because they are not the "experts" and they have the one thing that professionals often lack - time to listen. These services will be much more effective if they are backed by and integrated with the services provided by members of the caring professions (Parkes, 1993:296).

Referrals to voluntary agencies are by self-referral; not all bereaved parents may feel able to make initial contact, may not have access to a group in their area or may not wish to belong to a group. For these parents what else is available?

Support from the Statutory Sector

Psychiatry

Parkes (1993) has suggested that bereavement volunteers may obviate the need for referral to the "experts" who one could assume relates to psychiatrists. Davis and Fallowfield (1991) mention the use of psychiatric services, but as they point out there are both theoretical and practical reasons why they may not be appropriate. Most people whilst bereaved, are not ill. It is therefore reasonable to question the rationale of referral to psychiatrists trained largely in medicine, generally retaining an illness model and treating predominantly with drugs. In practice there are frequently delays inherent in referral to a specialist but there still exists the need for proper identification in making a referral by a G.P. (Davis and Fallowfield, 1991) It is doubtful that psychiatric services could cope with the extra work load, especially as they are stretched at present (Davis and Fallowfield,1991).

It could be suggested that in the absence of any other help, the bereaved are referred to psychiatrists when grief has become chronic, and a general practitioner feels out of his/her depth. It is possible that an extra burden is placed on the bereaved by referring them to specialists who are seen as dealing with "mad" people. This may stigmatise them even more. At present there are no studies to show how many bereaved parents or bereaved siblings are referred for psychiatric help, whether this is indeed helpful or whether this could have been prevented by continuing support from members of the primary health care team, or elsewhere from the time of death. However, it is interesting to note that Lazarre (1979), an American psychiatrist, estimated that 10-15% of people

who passed through mental health clinics, beneath their psychiatric disorder, were suffering from an unresolved grief (1979) Bowlby reinforced this statement by stating that:

> Clinical experience and a reading of the evidence leave little doubt of the truth of the main proposition that much psychiatric illness is an expression of pathological mourning, or that such illness includes many cases of anxiety state, depressive illness, and hysteria, and also more than one kind of character disorder (Bowlby, 1980:97).

More research is required to evaluate the work of psychiatrists in dealing with the bereaved, although it could be argued that better provision of support from the time of death, may avoid the need, in many cases, for referral.

Paediatricians

In relation to cot death specifically, Mandell (1988) sees the role of the paediatrician as being in a position to be helpful to parents, and to surviving children. He reports that parents consistently have said how beneficial it was when paediatricians took the time to listen to their concerns and problems. For parents whose children die from other causes, there is nothing in the literature which would guide paediatricians, or suggest that they play a key role in bereavement support. Essentially paediatricians are trained in the medical model of care and therefore are concerned with illness and disease. It is unlikely that paediatricians will have the time or the skills to consider supporting bereaved families over a long period of time. Cornwell's paper (1977) from Australia reports that of 19 families who experienced cot death, at least half of the medical practitioners directly involved did not see the plight of the bereaved parents as within their sphere of professional activity. The remainder believed they had an appropriate role.

The Primary Health Care Team

Most families are registered with a general practitioner and those with babies or young children are likely to be seen by health visitors. Whilst it could be assumed that general practitioners in particular would visit families whose children die suddenly and unexpectedly, there is little research to show that this is the case. Stewart (1993) suggests that parents need follow-up from health professionals on the day of death and subsequently by their general practitioner or health visitor. Continuing contact with members of the primary health care team provides an opportunity for parents to talk of their difficulties. In a later paper Stewart (1993a) sees the need to maximise the role of the health visitor by ensuring that there is direct contact with the hospital paediatric team. It could be suggested that lack of time prevents community health carers from giving support, but this would seem questionable. Davis and Fallowfield have noted that:

> The primary excuse given by doctors and nurses for not addressing the psychological concerns of their patients is lack of time. We suspect that this is not always the real reason. A more likely explanation is that lack of confidence and lack of skill in dealing with psychological issues through inadequate training, causes emotional discomfort. Hence clinicians utilise what time is available during a consultation to discuss the more practical, technical and physical aspects of care. Some doctors suggest that teaching psychological skills must mean that other more important parts of the consultation will be left out (Davis & Fallowfield, 1991:328).

The literature search revealed a paucity of information on services provided by members of primary health care teams, although reference to professional help is advocated (Stroebe, 1993; Vance, 1992; Raphael, 1983; Mandell, 1986). As the papers of Lopata and Rosenblatt (1993) suggest, informal social networks in the 1990's can no longer be assumed to provide adequate help. Family members, for instance, are no longer necessarily available when needed (Stroebe, 1993). Social networks can therefore not be taken for granted. More formal services must be provided to fulfil some of the former support functions of the family and close community. Whilst voluntary services are

more available to the bereaved than was the case some years ago, as evidenced by the rapid growth of self-help groups (Lieberman, 1993), Stroebe suggests that these should supplement professional services. She further suggests that:

> apart from humanitarian reasons, carefully planned care reduces chronic and long-term demands on health and social services and the number of days lost through distress, anxiety and sickness (Stroebe, 1993:472).

This would suggest that health care professionals should be involved in caring for families where a child dies, in offering support from the time of death and in the months that follow. Health visitors would seem ideal professionals to fill this role as they may already know the families, have skills in working with difficult family situations, and may know of local resources which may be of benefit. This does not exclude the voluntary sector who may be able to provide different and complementary support. Parkes (1993) has advocated the need for integration of the statutory and voluntary sectors, and indeed, the support of a family after the death of a child, would lend itself to a collaborative approach between the two agencies. Thus the ideal would be to involve health visitors from soon after a death, so that an assessment could be made of a family's needs for support, for health visitors to offer support if appropriate, for health visitors to work in conjunction with voluntary agencies or to withdraw if this was more appropriate. In other words, health visitors would be key professionals in monitoring/ giving or accessing further support. However, Raphael et al (1993) suggest that health systems and other interacting systems need to ensure that their policies are helpful for bereaved people and do not increase stress or add to risk of disorder.

Summary

The death of a child is fortunately a rare occurrence in the Western world, but its rarity inevitably means that those who do experience such a tragedy are isolated because of it. Those outside the close family, unaccustomed to dealing with such an event, fearful of

saying the "wrong" words, of breaking down or not knowing how to deal with the reaction of the bereaved, may avoid contact, thereby increasing isolation.

This chapter has highlighted the importance of support for the bereaved from others outside the close family, that is from friends, neighbours and/or professionals. Social support and the reasons for it have been described. Different types of support have been identified. Where support is lacking, health may be affected, thus putting an extra stress on the bereaved. Voluntary services available to the bereaved may not be available or suitable to all. Support from the statutory sector may be provided by paediatricians in the short term, or by psychiatrists when grief has become more complicated. The role of the primary health care team in supporting families where a child dies is given little mention in the literature, and yet it would seem an ideal role for health visitors, especially to fulfil. They may already be known to families, have skills in dealing with difficult family situations and may know other local resources to help the bereaved.

Having considered the extra-personal aspect of bereavement, the next chapter will discuss the methods and methodology of conducting research into *bereavement*, *with* specific reference to the studies presented in this thesis.

CHAPTER 6

THE METHODOLOGY OF THE STUDIES

Introduction

This chapter begins with a consideration of the methodological issues involved in bereavement research, and then continues with possible methods available to researchers in this area. Finally it sets out how methodological issues and methods have influenced the two studies in this thesis. This thesis aimed, in the first instance, to establish bereaved parents' perceptions of support from the statutory sector after the sudden, unexpected death of their children (from 1 week to 12 years). This will be referred to as Phase 1. Secondly, it aimed to evaluate a particular form of support for bereaved families, within the health service, by introducing an intervention to encourage health visitors to visit, so that families would feel better supported. The evaluation of this intervention from the parents' and health visitors' point of view, forms the second and major part of the thesis, and will be known as Phase 2.

It has been argued that research into everyday life can never be value-free or entirely objective in that scientific activity is itself a "human" relational enterprise (Phoenix, 1990). Therefore, those who conduct research are themselves vulnerable to the theoretical propositions they use in designing and carrying out research on others. I recognise that my present values have developed from my personal and professional

experience, a fact I must be mindful of as I reflect on the methodology of the study throughout this chapter.

Over the years, through running workshops on dying and bereavement nationally, I have come in contact with a wide range of professionals including many health visitors. I have also worked in the hospice movement with many dying adults and dying children, as well as with the bereaved of all ages. Therefore, my professional background may have contributed to my focus in a specific way. I have also known maternal death aged six, and sudden, unexpected spousal bereavement in my late twenties when I became a single parent to three very young children. Later I experienced the death of two unborn babies. Doubtless, these experiences will in some way affect my research. However, I see the experience I have gained over the years as a positive influence, without which it is unlikely that I would have entered this field.

My personal philosophy is one which recognises bereavement as a family affair where isolation of members both from each other and from society at large may make recovery more difficult and painful. For those who may have no family, then I feel society should take some responsibility to offer support. I feel a commitment to helping both the bereaved and those who work with them. Nonetheless, coming from a nursing background, developed from the medical model, and conducting bereavement research within a scientific medical department, has caused me some difficulties in adapting to the sociological model needed for this thesis.

Conducting research on the bereaved would appear to be a "sensitive" area, so the first part of this chapter considers what is meant by this and goes on to explore other issues which may raise ethical problems.

Methodological Issues in conducting Research into Bereavement

Sieber and Stanley (1985) have suggested that research on sensitive topics addresses some of society's most pressing social and policy questions. It is an area which illuminates the darker corners of society where the "taboo, the prescribed and the unusual all promote distancing experiences" (Rock, 197:25). Studies involving sensitive topics may therefore aid theory-building because they challenge taken-for-granted ways of seeing the world (Lee,1993). In addition, sensitive topics tax the methodological ingenuity of social researchers.

Bereavement research is considered a "sensitive" topic due to the fact that to question people who are recovering from the death of a significant loved one, may seem intrusive and thoughtless. However, one difficulty in talking about sensitive topics is that the phrase is often used in the literature as if it were self explanatory; the term is treated in a common-sense way without being fully defined or explained (Lee & Renzetti, 1990). For example, Sieber and Stanley define socially sensitive research as:

> studies in which there are potential consequences or implications, either directly for the participants in the research or for the class of individuals represented by the research (Sieber & Stanley,1988:49).

They do not specify the scope or nature of the kinds of consequences or implications they have in mind. As Lee (1993) suggests, their definition therefore encompasses all research which is consequential in any way. On the other hand, Farberow (1963) equates

sensitive topics with those areas of social life which are laden with emotion or inspire feelings of awe and dread. As this definition does not include all research, for example, deviance, Lee puts forward the following:

> Research which potentially poses a substantial threat to those who are or have been involved in it (Lee, 1993:4).

It is unclear as to whether he means the researched or the researchers, although he presumably means the respondents. In relation to bereavement, for a researcher constantly exposed to death and sadness, such research may well pose a substantial threat to their well-being. This will be discussed more fully later in the chapter. For bereaved respondents, "a substantial threat" needs some exploration as does Parkes' statement in which he considers that :

> there is a real danger that researchers will cause distress for bereaved persons and may even harm them (Parkes, 1995:171).

It was noted in Chapter Two that "death has been so obliterated from our culture that it is hard for us to imagine or understand it" (Aries, 1983:579).

Bereavement involves death, and because society generally denies it, it effectively shuns the bereaved, because its members do not wish to worsen an emotionally charged situation. In other words, society tends to avoid the bereaved to "protect" them, However, it could be suggested that the protection is for the outsiders. In terms of research, this issue is clearly important. It has been established that the death of a significant person may cause great distress and stress to family members (Raphael, 1984; Parkes, 1972; Worden, 1983) and so to intrude on their pain, to conduct research at a time when they are most vulnerable, may seem insensitive. To ask questions about

their feelings and to prompt reminders of the death and the deceased, may evoke a tearful, painful reaction, which may be the "potential threat" and "doing harm" that Lee and Parkes mention.

However, it cannot be assumed that all bereaved people wish to be left alone with their grief. Many, especially those whom society has avoided, may be grateful for an opportunity of expressing their pain to someone not closely involved. Provided effective informed consent has been given by the bereaved, and they have expressed a desire to share their experience, being involved in research may be beneficial. Cotterill and Letherby (1993) suggest that "narrative technique" is a valid sociological method for gathering data about people's lives. Whilst not specifically relating to bereavement, the therapeutic value of in- depth interviews has been noted by Brennan (1993), Cotterill and Letherby (1993) and Jorgenson (1991). Berger and Kellner (1964) also suggest that talk, conversation and discourse are crucial to the social construction and re-construction of family paradigms. Burkitt also argues that:

> Human agents are to be viewed as responsible, autonomous individuals who use accounting practices to construct their everyday activities and give meaning to them (Burkitt, 1995:62).

The fact that a researcher acknowledges and gives value to what is divulged by the bereaved, may give the mourners a greater sense of self-worth as well as helping them to bring some order to their shattered worlds through the expression of their feelings. Morgan (1985) stresses that in talking, conversation is not only about past experiences or future events but also is the principle process by which point and purpose is given to life's meaning. The death of a significant person, especially a child, may cause mourners to question the meaning of life and death. If there is no opportunity of expressing their

feelings, then isolation may be further increased. Thus the act of research involving them may be of great benefit, and may be the first time that they have had an opportunity of sharing their thoughts.

However, it is recognised that for some bereaved people, who would want to remain composed in a face- to- face interview, it may be difficult for them to do so. Being in control may be socially prized (Goffman, 1957; Sheff, 1988), therefore showing emotion and crying may compromise their values. Thus, doubts that one can maintain proper standards of poise when asked about painful situations may make matters more threatening. This is true also for the researcher who may have to share with those researched, feelings of unease, discomfort or emotional pain.

Rather than seeing the topic as sensitive, I believe that anyone conducting research into this area must be sensitive, because they are involved with people who may be emotionally raw. For this reason I would suggest that before embarking on research into bereavement, researchers should have knowledge of the grief process, be aware of their own feelings surrounding loss and know how to deal with distressed people. If, for example, in the course of an interview, the respondent becomes distressed, the needs of the respondent should take precedence over the needs of the research (Parkes, 1995). The decision to interrupt or to discontinue the interview will depend on the response to the support given by the interviewer and the participant's wishes. There is no place for scientific detachment. If the respondent is in need of help, the interviewer should not hesitate to provide it (Parkes,1995). Riches & Dawson (1998) in their qualitative studies on bereaved parents, recognised that their experience as a bereavement training

consultant and a lecturer in human relations respectively, lessened ethical dilemmas arising from possible criticism of "poking around" in other people's emotions and helped them deal with any painful reactions. Researchers are responsible for any problems that arise as a result of the research itself; thus it may also be important for researchers to know of local or national agencies that are available to help the bereaved, so that respondents, feeling raw and in need of help after an interview, have someone to contact.

Support for Researchers

Parkes (1995) has suggested that because of the emotive nature of the work, all interviewers working with the bereaved should be closely and regularly supervised by someone with a sound knowledge of bereavement and counselling as well as a clear understanding of the purpose and method of the research and ethical issues involved. By monitoring a researcher's response to the work, and ensuring that (s)he is coping well, it is likely that good rather than harm will come to the respondents (Parkes, 1995). Even for those not in paid research, researchers need to be mindful of their own needs in dealing with the bereaved. Cook and Bosley (1995) have commented on the effect of the emotionality of grief research on researchers, but do not address how to manage it except for the scheduling of interviews with time in between. Coyle and Wright (1996:435) advocate that researchers be provided with "social and emotional support", by formally organised supervision from peers. But as Rowling (1999) suggests, the supervision suggested denotes a formal, clinical purpose of monitoring for adherence to professional practice guidelines and protecting the participants. She suggests that whilst the study of grief on those researched is a sensitive area, what has been ignored is the

emotionality and meaning of the research for all those involved -not just the participants, but also the researchers (Rowling, 1996b). She has highlighted that while ethical dilemmas have been considered in relation to participants, little attention has been paid to researchers and their needs, especially in relation to qualitative studies. In conducting a study on grief in school communities in Australia (1999), she identified self-reflexivity as a key factor for researchers in the field of loss and grief. By keeping a research journal of her own thoughts and feelings about problems encountered, her emotional reactions to interviews, and aspects of the research that concerned her, she was helped in processing her own reactions.

The Ethics of Bereavement Research

For all of those actively involved in academic research, the development and application of research ethics is required, not only to maintain public confidence and to protect individuals and groups from the illegitimate use of research findings, but also to ensure its status as science. For this reason, ethical committees in health authorities act as gate-keepers to ensure that the best interests of all are protected and that the conduct of research follows a set of principles which guide it.

Barnes (1979) defines ethical decisions as those which arise when we try to decide between one course of action and another, not in terms of expediency or efficiency, but by reference to standards of what is morally right or wrong. Therefore ethical decisions are not being defined in terms of what is advantageous to the researcher or the project. They are concerned with what is right or just, in the interests of not only the project, its

sponsors or workers but also with those who are participants in the research. Within this consideration based on ethics, a number of factors are relevant.

Informed Consent

The case of informed consent is especially important in conducting research into the bereaved. These may be vulnerable people but they should still be seen as capable of making informed decisions; thus it would seem right to give them choice in being involved in research either by interviewing or by completing questionnaires. Only they can judge whether they can cope with an interview, a questionnaire, or neither.

According to the British Sociological Association (1991), informed consent implies a responsibility on the sociologist to explain as fully as possible, and in terms meaningful to participants, what the research is about, who is undertaking it and financing it, why it is being undertaken and how the findings will be disseminated.

The British Sociological Association (1991) also stresses the principle that informed consent should be obtained directly from research participants, while at the same time taking account of the gate-keepers' interest. This is not only based on a complete understanding of the aims and processes of the research itself, but also may be assumed to encompass any consequences that may follow from its publication in the public domain (May, 1997). A researcher might, and in all cases ought, to take all possible steps to protect the identity of any person, in the anticipation of it being used for purposes other than intended. Thus guarantees of confidentiality and anonymity given to

research participants must be honoured (British Sociological Association, 1993). However, before informed consent is gained from possible respondents, identification of those to be researched must be ascertained.

Gaining Access

Sanders (1980) has suggested that one cannot hope to "learn the ropes" in doing field research without suffering "rope burns". He argues that people need to carry out tasks which run against the grain; thus it is difficult to avoid the fear of being a stranger, of rejection when seeking details of people's lives, and of violating the normative standards of those being studied. The studies of Walford (1987), Johnson (1975) and Punch (1979) have all shown that researchers can suffer from physiological stress. However, as Lee puts forward:

> The draw-back is that in stressing the difficulties of field research, what results is largely a set of "heroic tales", in which the reluctance of those being studied is overcome as a result of the researcher's diligence, cleverness or artifice (1993:121).

In other words, the difficulties are minimised, and turned round to be assets attributed to the researcher.

Gaining access to information on the bereaved requires detailed planning and may take several months, especially if access is required to hospitals or public records. Access to bereaved people can be achieved in a variety of ways, including public records of death registrations, hospital records, obituary notices, referrals from funeral directors and

referrals form G.Ps. Guardians are right to check the credentials of the researcher and the validity of the research, but as Parkes suggests:

> they often err on the side of being over zealous, depriving people of the opportunity to help with well-founded research and forcing researchers to make use of non-random methods of sampling (Parkes, 1995:172).

However, Fielding (1982) and Polsky (1971) suggest that many of the problems of gaining access hide a reluctance to go out and face those problems by actually entering the field. Lee (1993) further suggests that there is usually little incentive for a researcher to dwell on the reasons why a request to grant access was refused. The pressure to move on to seek entry to another site is usually too great. Nor are researchers necessarily wise, while in the field, to look closely at why access has been granted. Lee (1993) suggests that in so doing, they might raise further and unwelcome questions in the minds of the gate-keepers about whether the decision to allow entry was right in the first place, or in their own minds, the legitimacy of the access they have been granted.

Much of social science writing on field research in general, and access in particular, is based on the researcher's own account. As Lee (1993) suggests, it is usually the one part of a study which is only written from one side. What is lost, therefore, are the understandings of those being studied (Warren, 1984; Bittner, 1973). Survey researchers face a similar problem when they try to use survey methods for the study of non-respondents. It would appear that this is an area of bereavement research which has not been given much attention.

Although not specifically about bereavement, Form (1971;1973), for example, has pointed out that there has been very little attempt to systematically examine the social dynamics of access processes, to consider patterns of access and non-access across studies, or to consider the potential consequences of differential accessibility to some settings rather than others.

Once access has been gained, and informed consent given by possible respondents, the researcher is then in a position to collect data by the chosen means. Possible methods for conducting bereavement research will be discussed later in this chapter.

Having collected data, the researcher is then ready to analyse the results, where objectivity is important.

Objectivity and Evaluation

Objectivity is considered a fundamental characteristic of a science (May, 1997).

It is often assumed that if our values do not enter into the research, it is objective and above criticism. Objectivity is therefore defined as :

> the basic conviction that there must be some permanent, ahistorical matrix or framework to which we can ultimately appeal in determining the nature of rationality, knowledge, truth, reality, goodness, or rightness (Bernstein, 1983:8).

As May (1997) suggests, many people accept what scientists say is the "truth". But the subject matter of the social sciences is social life itself and researchers are part of

society, so is it possible to be completely removed? In taking a positivist approach, the aim is to collect and assemble data on the social world from which we can generalise and explain human behaviour through the use of theories. Empiricism, likewise, shares the belief that there are facts which can be gathered on the social world independently of how people interpret them. However, positivism is theory-driven and designed to test the accuracy of the theory, whereas empiricism is a method of research which lacks, or more usually has not referred explicitly, to the theory guiding its data collection procedures. In other words, as Bulmer suggests "the facts speak for themselves" (Bulmer, 1982b:31). In relation to realism, the task for researchers is "to organise one's concepts so as to grasp its essential features successfully" (Keat and Urry, 1975:112). If researchers content themselves with studying everyday social life, such as conversations and interactions between people, this may distract them from an investigation of the underlying mechanisms which make these possible in the first instance. The task of researchers then is to uncover the structures of social relations in order to understand the reason for policies and practices. Realism argues that the knowledge people have of their social world, affects their behaviour and unlike the propositions of positivism and empiricism, the social world does not just exist independently of this knowledge. This would seem especially relevant to the bereaved who may behave in a certain way because that is what society expects. Also, a realist concept would not necessarily assume that we can "know" the world out there independently of the ways in which we describe it. Again, this would appear particularly relevant in bereavement research where each individual will grieve differently, regardless of the "stages" identified by researchers.

Therefore, subjectivity is obviously part of bereavement. To concentrate on subjectivity we focus on the meanings that people give to their situation rather than the environment itself. Contrary to the positivist view, researchers cannot know with certainty how bereaved people interpret the world around them; so research using the subjective paradigm must focus on bereaved people's understandings and interpretations of their social world.

As mentioned earlier, bereaved people are constantly engaged in the process of interpretation. Social life cannot simply be observed (empiricism); it can only be understood as the result of examining people's selection and interpretation of events. Understanding these processes and the rules which make them possible is the aim of idealism. It is not explaining why people behave in certain ways, but how people interpret the world and interact with others. Our accounts of the social world must therefore be "internalist", that is arising from within the culture of bereaved people. In undertaking the research in Phases 1 and 2, although the empiricist view point predominates, there are parts which are built on realism.

Having considered ethical issues and different sociological approaches to research, different ways of conducting research into the field of bereavement will be discussed.

Choosing a Method for Bereavement Research

Research into bereavement, like any other subject, involves fact-finding, either to prove a hypothesis, to establish attitudes or opinions, or to find out more about collective life in our society. Thus it involves choosing an appropriate method of questioning to elicit information. This can be done either by a qualitative study, collecting data by interview or using a quantitative method, which involves carrying out a survey by means of self-completion questionnaires or telephone interviews. Field research, based on qualitative methods such as participant observation or in-depth interviewing, has often seemed like the method of choice in studying sensitive subjects (May, 1997). For some studies it may be sufficient to question a small sample; for instance, Riches and Dawson (1997) conducted a small scale study into the impact of a child's death on marital relations in fifteen couples. This involved in-depth interviews producing much rich data on the lived experiences of couples, thereby giving some insight into the difficulties suffered by both fathers and mothers. However, a study seeking to establish parents' perceptions of different kinds of support available after the death of a child, is likely to benefit from a larger-scale study to ensure that the views obtained are representative of the general population. Also support structures for bereaved families within the voluntary and statutory sectors may vary in rural and urban populations, ethnic minorities may have less or more support, and some areas may have recognised needs more than others. Some areas of the country may have more financial resources to spend on bereavement care, particularly in relation to training professionals. Therefore, in conducting a large scale study, in order to gain an overview, such considerations are vital. A small scale study would only give a small sample of parents' views which would not necessarily

reflect the wider population or the resources available in other parts of the country. In this case a postal survey may be the best means of obtaining data, due to the distances covered, and the need for a sample size in different areas of the country.

Whilst telephone interviews may be appropriate for consumer research, it may seem insensitive and less confidential to the bereaved to talk of their grief by this method. Even if informed consent and a pre-arranged time of contact is assured, the bereaved person's situation may have changed for the worse since the agreement, as mood swings in the bereaved are not uncommon.

Postal Surveys

There is some debate about what should properly be called a questionnaire (Newell, 1993). Sometimes it is used to mean a document containing a set of questions for respondents to complete themselves (a "self-completion" questionnaire) or alternatively it can mean a list of questions which an interviewer reads out to respondents. Questionnaires follow a standardised format in which most questions are pre-coded to provide a list of responses for selection by respondents. In a postal survey, questions must be phrased so that they are easily and readily understood because respondents will not be able to obtain help with anything they do not understand. Open-ended questions leave informants with a space to write in their answer as they so choose. Closed or pre-coded questions are those which ask the respondent to choose one (or more) from a set of pre-selected answers. These can range from the simplest Yes/No, through 5-point rating or ranking scales to a choice from a checklist of alternatives. The main advantage

of using questionnaires is that a large population can be surveyed relatively cheaply. Costs are lower because interviewers are not used and pre-coding and computerisation speeds up analysis which is of benefit to the researchers. It is also possible for respondents to complete questionnaires at a time convenient to them, and in the case of the bereaved, allows an opportunity of taking a break, if necessary, from the painful subject.

As mentioned earlier in this chapter, it is not known how the bereaved view questionnaires. Although there is some evidence that respondents prefer to complete sensitive questions themselves, rather than face- to- face interviews (Siemiatycki, 1979), bereaved relatives whilst completing a questionnaire, may not necessarily like it. In Phase 1 of this thesis, three parents out of 67 mentioned how good the questionnaire was and how grateful they were to have been asked. Rather than being upset at completing questionnaires, most parents indicated that they were pleased to have been asked for their help and wanted to improve care for other parents and their families. One father asked why the questionnaire hadn't come sooner, and another stated: "We could have gone off our heads here. No-one cared until your questionnaire came". Several parents mentioned the fact that it had been good to have been asked their opinions as "most people are afraid to ask questions". The bereaved parents were asked if they could be contacted again if there was a need. Of 67 parents who responded, only one father was unwilling for further contact. It could be assumed therefore that those who replied were satisfied with completing questionnaires, and were willing to provide more information.

The following section looks at questionnaires from a different viewpoint, that of the researcher. One of the main arguments in using questionnaires, is that a poor response is likely. Addington-Hall (1998) found that postal questionnaires were an acceptable alternative to interviews in retrospective bereavement studies. Involving bereaved spouses, she considered whether the response rate and response bias in a postal survey about the last year of their spouses' lives, differed significantly from those in an interview survey, using the same measure. Neither differed significantly between the two groups, indicating that a postal questionnaire is a satisfactory method for data collection. The following table shows that both postal and interview methods are similar in relation to collecting data from bereaved parents, and in fact some of the highest responses are from questionnaires.

Table 3. Response Rates using questionnaires & interviews

Researcher	N=	postal questionnaire	interview	Response Rate
Lehman (1987)	41		yes	45%
Nixon (1977)	49		yes	47%
Defrain (1978)	50	yes		64%
Videka Sherman (1982)	667	yes		59%
Shanfield (1987)	76	yes		53%
Dyregrov (1987)	117	yes		54%
Finlay (1991)	150	yes		80%
Hazzard (1992)	36		yes	50%
Ostfield (1993)	86	yes		44%
Vance (1993)	252		yes	64%
Thuen (1997)	630	yes		40%

In conducting research into bereaved parents, it is now recognised that a poor response is likely as many parents move away soon after the death (Defrain and Ernst, 1978; Nixon and Peart, 1977; Lehman and Wortman, 1987). This was confirmed in Phase 1 where it was established that at least 14% of the parents had moved within three years from the death. In Phase 2, 11% of the families were untraceable at six months from the

death. By using postal questionnaires, where there is no response, the researcher is left in doubt as to whether the family has moved or whether the parents had received them but felt unable to complete them. Therefore this is a disadvantage of this type of method which is less likely to happen in interviews.

Face-to-Face Interviews

If face-to face interviews are chosen as the means of data collection, interviewers need to be provided with some form of document to guide questioning; this may be of both pre-coded and open-ended questions. An interview schedule contains set questions in a predetermined order adhered to at each interview, whilst a focused interview will list areas to be covered, but leaves the exact wording and order of the questions to the interviewer. This allows for a more non-directive approach in which the interviewee's replies determine the course of the interview. Such a method may be more appropriate with bereaved people as they may want to tell their story in their own way, but this will depend on the sort of information required from them. Interviewing can have both advantages and disadvantages. Interviews can be more flexible and, in the hands of a skilled interviewer, extract more information from the individual than a postal questionnaire. Participant observation, or ethnographic research, is about engaging in a social scene, experiencing it and seeking to understand and explain it. The researcher is the medium through which this takes place. By listening and experiencing, impressions are formed and theories considered, reflected upon, developed and modified. Participant observation is not an easy method to perform or to analyse, but it is a systematic and disciplined study which, if performed well, greatly assists in understanding human

actions and brings with it new ways of viewing the social world (May, 1997). However, it takes longer and is more expensive than questionnaires, due to the cost of paying the interviewer in terms of travel costs, time and analysis of the data. It is also possible that the interviewer may be biased.

Some bereaved people, especially parents, may have difficulty in accepting this method. Defrain and Ernst's (1978) study found that parents bereaved as a result of cot death, had included in their written replies that they did not think they could handle an interview. As one mother noted:

> I would write a page and cry, put it aside a few days and then write a page and cry. If an interviewer had come to my door, I'd have broken down completely (Defrain and Ernst, 1978:987).

Having considered methodology and possible methods, the next section will report on how these have related to the two presented studies, that is, Phase 1 and 2.

Methods of Research for Phase 1 and 2

Aims of Research

The research aim of Phase 1 was to establish bereaved parents' perceptions of care after the sudden, unexpected death of their child (from 1 week to 12 years) and to further determine how confident health professionals and members of voluntary agencies felt about supporting them.

Using the results from Phase 1, the main aim of Phase 2 was to evaluate the efficacy of an intervention for health visitors to use with bereaved families, the main hypothesis being that for those families whose health visitors had used the intervention, families would feel less isolated and better supported.

Chosen Methods and Geographical Areas for Studies

In conducting Phase 1, the method chosen was quantitative, using postal questionnaires as the means of data collection. Of the 14 regions at that time, 7 were selected taking into account geographic, socio-economic, urban, rural and ethnic factors. The regions in the study were Northern, Trent, East Anglia, North East Thames, Wessex, Mersey and Wales. Two health districts were chosen randomly from each region to gain a broad picture of care across each region. For the sake of confidentiality, these are not named.

The study method chosen for Phase 2 was a randomised controlled trial, using postal questionnaires as the means of data collection. The area selected was the South & West region of England because it was the region that I worked in; also funding for the project was sought and obtained from the Research & Development Directorate (South & West). The region is made up of Avon, Cornwall, Devon, Dorset, Gloucestershire, Hampshire, Isles of Scilly, Isle of Wight, Somerset and Wiltshire. There is a mix of urban and rural areas with a population of 6.6 million (ONS,1995). There are 23 health districts within the area with 15 acute hospitals serving the regional population. A randomised controlled trial was chosen as the best means of evaluating the intervention. By using this method, a control and a study group are identified from the outset and a

comparison can be made of any differences that the intervention has made. The randomisation in this study lies in the 23 trusts within the South & West region; the community trusts in these districts were stratified according to the rural/urban nature of their populations and, within strata, allocated randomly to two groups: control- with no intervention (n=11), and study -introduction of intervention (n=12). Randomisation by trusts was chosen because of the way in which health care delivery by health visitors is structured within general practices. It would be difficult for a single health visitor to care for two families randomised to different groups and health visitors working within the same practice would be likely to share their knowledge and experiences.

The question format was based on that of Phase 1, as this had proved successful in obtaining data. As data was needed not only from all fathers and mothers in the South & West region, whose children died during the study period , but also from their health visitors, the possible numbers of respondents, was likely to be approximately 300. Even with the allotted time span of two years for data collection, with this number of respondents and the distance involved, interviews would have been unrealistic. A large sample size was necessary to determine any differences that the intervention may have made. As the information needed from parents and health visitors was easily obtainable from simple questions, postal questionnaires were considered the best method.

Ethical Difficulties

Of the 15 ethical committees approached in Phase 1, 13 gave permission to conduct the study. One ethical committee refused entry from the outset stating that by answering the

questionnaires "parents might question why they were not offered certain facilities or care." Such a remark could assume that the ethical committee felt threatened by the study and may even have thought that parents might take action against the health district for not providing certain care or facilities. In another health district, local paediatricians were asked by their ethics committee to decide whether the study should be undertaken, before it went before the ethical committee. Paediatricians initially refused permission, saying that similar research was in progress, but on further investigation, this was found not to be the case. After lengthy negotiations with the paediatricians, the proposal eventually went to the ethics committee, and permission was granted. However, due to all the delays, it was too late to enter that particular health district into the study. It could be argued that again this study posed a threat. By taking so long to give a decision, the paediatricians and the ethics committee may have hoped that their health district would not be included.

It raises a further point. Instead of one group of "gate-keepers" there were two. It would seem more appropriate to have had a paediatrician on the ethics committee which would save time. The ethics committee is recognised as the main "gate-keeper". Their involvement of paediatricians, highlights the fact that all concerned may have felt uneasy about what the study results may have produced.

In conducting Phase1, all ethics committees within the study area made G.Ps' permission a requirement before approaching bereaved parents. While on the one hand, this imposition reduced the study sample considerably, as many G.Ps either didn't reply to our letters or did not give permission to approach the bereaved parents, on the other

it took choice away from possible respondents, by not allowing parents to be approached directly. It could be argued therefore, that by imposing such a condition, the ethics committees were either protecting the interests of the G.Ps or were being overly cautious in protecting the parents. Whatever the reason, parents should have been allowed to make their own decision.

In Phase 2, no such restrictions were made. The reason for this change is unknown. It could be suggested that because the study was in a different geographical area, their ethical committees took a more enlightened attitude. Having conducted one major study and published the results, indicating that G.Ps blocked access, note may have been taken. Further, it could be that the focus of the research was on health visitors' care, not G.Ps, so G.Ps did not require the same protection.

Whilst most researchers carry out research on the bereaved with good intentions, I recognise, however, that there may be some who, like the media, have voyeuristic and ulterior motives in approaching the bereaved. Comments from bereaved parents in Phase 1 demonstrated the upsetting nature of the contacts:

> I was in too much of a state of shock to remember, but I know that because we refused a photo of our son for the front page, they wrote a load of fabricated crap! The media have no feeling. Their only thought is for sales.

> Totally horrifying! It was one of the most distressing parts of the tragedy!

> We were all deeply upset, especially when we didn't know there was to be anything in the papers. It was like our daughter dying again.

Whilst the media is not governed by ethical committees, because it is not involved with research as such, it does pose a problem. Sadly the sudden death of a child is news-worthy material, which necessitates fact-finding as soon after the death as possible. Some parents in Phase 1 stated that interviews with reporters had been sensitive, others were horrified by the insensitivity. Thus it could be suggested that newspapers should adhere to a code of good practice particularly for their employees dealing with painful areas involving death.

Gaining Access

In conducting Phase 1, it was necessary to obtain information from thirteen health districts on families whose children had died suddenly. Child deaths are listed with those of adults, although in some districts the Child Health Computer Service was able to supply the relevant information. In one, all child deaths were coded according to OPCS codes, for which the key was not easily available, so obtaining the appropriate information took several months. Where the Child Health Computer Service could not help, the study relied on the relevant children being identified by a local paediatrician who then sent only the names. We then relied on secretaries for further information on parents' addresses and G.Ps names and addresses. In two health districts, whilst having the relevant information on the families, we did not have the names or addresses of G.Ps. As it was required by all ethical committees that the G.Ps were asked for their permission to contact the parents, it was necessary to have this information. Despite repeated attempts to secure it, it was withheld, so that 42 families (18%) had to be excluded from the study.

Gaining access to families thereafter was thwarted by the fact that nearly a quarter of G.Ps (24%) did not reply to our initial letters or to subsequent follow-up. Thus a further 54 families had to be excluded, because permission to contact them had not been given. Of the remaining families, permission to contact them was granted by 70% of G.Ps. For those G.Ps who did not want us to contact the parents, reasons given were that parents were still grieving, had divorced or separated since the death, that some mothers were pregnant, that there were court proceedings as a result of the death, or that there were social problems. Whilst it would seem that the G.Ps may have been protecting the parents on the whole, the reasons given for not approaching them seem insubstantial. It would seem appropriate that some parents were grieving, that those who had divorced or separated may have done so because of lack of support and might have valued an opportunity to share their feelings, having experienced two major losses. Those mothers who were pregnant were still able to make a decision themselves, as were those with social problems, and those involved with court proceedings, although legal questions may have applied here. From a possible 226 families, because of lack of information or refusal to contact them, only 72 families remained in the study. It is interesting to note that in the pilot study health district where the response was the highest, although the G.P was sent a letter, if there was no reply within three weeks, the parents were contacted directly. Ethical committees in other districts did not give approval for this approach.

This study is a good example of how gaining access to information can be blocked, and how ethical committees and G.Ps in particular, did not appear to welcome consumer

input to gain a better picture of bereavement care. The study sample was considerably reduced not only because information was not divulged but mainly because of the restriction of seeking G.Ps' approval in the first place, imposed by the ethical committees.

In Phase 2 conducted in the South & West region, any family who had experienced the sudden, unexpected death of their child (from 1 week to 12 years) from accident or illness, were eligible for the trial over the two year study period together with their health visitor. Access to information relied on the help of the existing CESDI network (Confidential Enquiry into Sudden Deaths in Infancy), and hospital and ambulance personnel throughout the region. When a child died suddenly and unexpectedly, they were asked to report the death immediately. This was backed up by asking identified personnel in hospitals which dealt with children, to telephone with details as soon as possible. Every six months a reminder was sent to all concerned in reporting. Any deaths missed were picked up from the child death returns for the region, issued monthly. Thanks to the co-operation of those concerned, all sudden childhood deaths in the region were identified, and relevant information on the families was forthcoming. This was in direct contrast to the experience of Phase 1.

Informed Consent

As was discussed earlier in this chapter, it was vital to obtain consent from bereaved parents before sending questionnaires. For this reason bereaved parents in both Phase 1

and 2, were sent a letter asking for their help, explaining the nature of the research, giving information about the researcher(s), and stressing confidentiality of any information given. The letter to parents in Phase 2 is shown in Appendix 3. If they did not wish to participate, they were asked to return the tear-off slip in the stamped addressed envelope provided, and no further contact was made. If this was not received within two weeks, a questionnaire was sent.

Questionnaire and Intervention Development

In both Phase 1 and Phase 2, questionnaires for bereaved parents, were developed with the help of bereaved parents and health care professionals, taking into consideration a "user friendly" document for bereaved parents and breaking down the questions into sections, so that parents could take a break if necessary. The same questionnaire was developed for fathers and mothers. In Phase 1 questionnaires were designed for either a girl or boy who had died. The questionnaire shown in Appendix 1 is for girls. Health professionals in both studies assisted in the questionnaires for health professionals and voluntary agencies.

In Phase 2, the development of the intervention in the form of an information pack for study health visitors to use with bereaved families, was guided by health visitors and bereaved parents. A group of 4 health visitors from one health centre outside the area, with varying experience, helped in the construction of the bereavement assessment tool and information booklet for health visitors. Within Avon, four parents bereaved for at

least a year, were asked for their help and guidance on the construction of the information booklet for bereaved parents.

Pilot Studies

In both Phase 1 and 2, pilot studies were conducted outside the study area to determine whether the necessary questions had been asked, all unnecessary questions omitted, and whether the layout and design was straightforward and clear to respondents. As a result, minor alterations were made to the questionnaires in both studies. In Phase 1, as there were few changes to the parents' questionnaire, the data were used in the final study.

Administration of Questionnaires and Information Packs

In Phase 1, questionnaires to bereaved parents, health professionals and voluntary agencies were sent out in two lots to ease data entry. If the questionnaire from parents had not been returned within two weeks, a reminder was sent. In the case of health professionals and voluntary agencies two reminders were sent if necessary at two weekly intervals.

Prior to the start of Phase 2, health visitor managers in the study group were sent information packs (n=796) for distribution to their health visitors to use if a sudden child death occurred over the study period. For each death in the study group, the relevant health visitor was contacted to ensure she had the intervention (Appendix 2).

Questionnaires to all relevant health visitors in both the study and control groups, were sent at three months from the death to assess their care plans (Appendix 4). A reminder was sent two weeks later if no reply had been received. Those parents who had agreed to be part of the study, were sent questionnaires (Appendix 4) at six months from the death, as this was felt a suitable time after the death to contact them. If no reply had been sent by two weeks, a reminder was sent.

Support for Bereaved Families

In Phase 1, the parents, who had been bereaved from 6 months to three years, were advised to contact their health visitor or G.P. in the first instance if they felt they required support as a result of the questionnaire. If these professionals were thought to be inappropriate, the names and telephone numbers of national bereavement help-lines were given on the questionnaire. Both the Child Death help-line and the help-line of the Foundation for the Study of Infant Deaths agreed to assist parents if necessary. In Phase 2, those in the study group had information on national agencies in the information booklet. For those in the control group, no national names or telephone numbers were given but the researcher's telephone number was given to all respondents in case of any difficulty.

In both Phases 1 and 2, hand-written cards of thanks were sent to those parents who returned questionnaires.

Support for Myself

Although I was not conducting interviews, I recognised the need for support for myself in conducting Phase 1 and 2, as much of the data was distressing. In Phase 2, I was conducting the trial on my own and therefore valued fortnightly co-counselling sessions with a colleague and also being part of a support group of professionals dealing with bereavement issues.

This chapter has outlined methodological issues in bereavement research, and considered possible methods in undertaking research into bereavement. Using these principles, the methodology and methods of conducting Phase 1 and 2 have been reported. The next chapter will consider the results of Phase 1.

CHAPTER 7

THE RESULTS FROM PHASE 1

Introduction

As has been demonstrated in the earlier part of this thesis, research to date on sudden, unexpected death of children has focused mainly on emotional sequelae of parents and siblings. Finlay and Dallimore's study (1991) was the first published study to determine parents' views on how the death of their child had been handled. Their questionnaires to 122 bereaved parents concentrated on hospital care prior to death or immediately afterwards. It would appear that no published empirical studies have considered bereaved parents' perceptions of longer- term care in the community and whether members of the primary health care team or voluntary agencies feel able to offer sufficient support. However, for three separate periods within the last twenty years, the Foundation for the Study of Infant Deaths has collected information in England and Wales by means of questionnaires from bereaved parents who have suffered sudden infant deaths (F.S.I.D.,1974-1981, 1984, 1985-1987, unpublished). The parents were self selected in that they made contact with the Foundation either through the head office or through a local branch. The main findings were that after the death of their child, parents felt the most helpful support came from partners, family and friends, and that local support groups were valuable sources of help. The results, whilst of great importance, cannot be assumed to be representative of the whole population of bereaved parents, especially as these parents had access to local support groups specifically concerned with cot death. The original proposal for Phase 1, initiated and funded by the

Foundation for the Study of Infant Deaths (FSID), focused solely on parents' perceptions of support after cot death. However, as the number of cot deaths had declined rapidly in the three years preceding the study, it was felt that there would be insufficient sample size to conduct a national project. For parents whose children die suddenly and unexpectedly from other causes, it is unknown as to what support is available to them. For this reason, Phase 1 concentrated on two things: firstly bereaved parents' perceptions of care after their child (from 1 week to 12 years) had died suddenly from whatever cause where parents had been bereaved from six months to 3 years, and secondly whether those working in the statutory and voluntary sectors felt sufficiently confident and able to support them.

Cot death is normally limited to children under one year, occasionally under two years (Mage, 1996). Little research has concentrated on the support of families of children who die from other causes in the older age range. The study, therefore, included parents within the chosen health districts whose children aged from 1 week to 12 years, had died suddenly and unexpectedly from accident or illness within the preceding three years.

This chapter will consider the findings from the parents, hospital staff, G.Ps, health visitors and voluntary agencies in particular, as they relate specifically to this thesis. However the data from Phase 1 also included important data from ambulance personnel, national voluntary organisations, the police, fire brigade officers and hospital chaplains. The parents also gave information on how they felt their child's funeral was handled, the manner they were treated in relation to post-mortems and in registering the death. While these results are important they have not been included as this thesis relates particularly

to support in the community in the months following a sudden child death (See Dent et al, 1996a).

The Study Sample

Of 226 families in the study base, 72 families remained after exclusions. The reasons for this high attrition rate have been mentioned in the previous chapter. Of the 72 families contacted, 42 returned questionnaires (including 5 of the further 8 cases from the pilot study). Table 1.1 shows the breakdown of responses.

Table 1.1 Responses from Parents

Questionnaires returned		**No of Families**
from both parents	50	25
from mothers only	15	15
from fathers only	2	2
Total	**67**	**42**
Response Rate = 58%		

This response rate accords with other studies of a similar nature. (Dyregrov, 1987, 50% response rate; Defrain, 1978, 60%; Hazzard, 1992, 50%; Videka-Sherman, 1982, 59%; Lehman, 1987, 45%). Whilst replies came from over half the parents in the study sample, 30 (42%) families did not reply, and therefore those parents gave no opinion of their perceptions of care and support. More responses came from mothers (60%) than from fathers, so the data presented is more representative of maternal bereavement. Thus, it cannot be assumed that those who did reply are necessarily representative of the whole bereaved parents' population. Similarly all but one family were white, so there is no real data to show how ethnic families were supported.

Cause of Death, Age and Gender of Children who died in the sample

Of those in the study sample who had suffered sudden child death, cot death accounted for 45% of the deaths, 38% from illness, 14% from accident and 2% from unknown causes. The age of the children who died ranged from 2 weeks to 10 years. The majority of the children who died were less than 1 year old (61%), mostly as a result of cot death. Thus parental response was from those who had suffered cot death than from any other group. Of the 42 deaths, 13 were girls and 29 were boys.

Statistical Methodology

No direct comparisons can be made in this study between the parents' and health professionals' responses as the health professionals contacted are not necessarily the ones who dealt with the families identified; thus the statistical analysis will be purely of a descriptive nature. The denominator used in the analysis, N, will vary, depending on: parental opinion, in which case, the less satisfied parent's opinion of the two will be taken, the individual opinion of the parents, in which case, all parental opinion will be used, and the number of parents or sets of parents to which a specific question is applicable (for example, those parents who have other children), in which case N will vary.

Parents Perceptions of Care and Support

In Hospital

Several researchers have recognised that everything that is said or done regarding the death of a child has great significance for the bereaved family. The bereaved may examine for weeks the statements and actions of hospital staff, and the events of the day of death may be played back for a lifetime (Henrietta, 1982; Soreff, 1984; Korth, 1988). For these reasons, parents in the study were asked how they had been treated in hospital. Table 1.2 shows the results.

Table 1.2 Parents' Satisfaction with Hospital Care

Service	N=	Good	Average	Bad
Care of Child	26	92%	4%	4%
Communication	30	77%	10%	13%
Helpfulness	30	80%	17%	3%
Efficiency	30	83%	13%	3%

N = Less satisfied Parent

Given that the opinion of the less satisfied parent has been chosen where they differ, parents reported that the service provided by hospitals was good on the whole, especially on caring for their child. Both helpfulness and efficiency were rated highly by the parents. Whilst 77% of parents thought that communication with hospital staff was good, 13% perceived it as bad, which suggests that in some hospitals communication with parents could be improved.

Being told of the Death

The most basic of human responses to those who are grief stricken and distressed involve the offering of comfort and consolation (Raphael 1984). This comforting is usually most necessary at the acute time of loss, when the bereaved receives the news of the death, or when the reality of the death finally breaks through the initial shocked denial. Those who have been professionally trained to other models may find it difficult to offer comfort because it represents the human side of their response, something they may have learned to detach or dissociate in some therapeutic frameworks (Raphael 1984). For the bereaved, even the simplest touch may convey much more than formal words; the very humanity and empathy of the caring person's involvement with his/her pain, something that is vitally important to the bereaved at such a time (Raphael 1984). In Finlay & Dallimore's study (1991) those parents who had been told of their child's death sympathetically, had specific features: interviews were unhurried and conducted in private; parents felt respected and the informant had a caring and understanding attitude; sufficient time was allowed for questions as the news was digested and the interviewer checked that the news was understood.

In Phase 1, for two thirds of the cases, the doctor involved spoke to the parents and confirmed the death of their child. Twenty eight parents could still recall the words used. No parents commented that this had been done badly. Over half the parents said how sensitively they had been told, the following comments from three parents demonstrating clearly that they appreciated human response from professionals and recognised how difficult it was for them.

They were very caring. It must have been a hard thing to do.

She was very sympathetic and comforting. Nobody could have been better.

We were told very, very sensitively by the doctor in charge, told with some emotion and sadness which helped us enormously.

These were encouraging findings, demonstrating that hospital staff appeared to handle child deaths with some sensitivity. In Finlay's study (1991), police were rated as more sympathetic than doctors or nurses, so again it would seem reasonable to suggest that sensitivity shown by hospital personnel may have improved since their study.

Bereavement Support for Parents

In Murray and Callan's study (1988), a consistent predictor of better adjustment to the death of their child was the parents' level of satisfaction with the comfort and support provided by doctors, nurses and other hospital staff. Greater satisfaction with the support from hospital staff also predicted higher levels of self-esteem, as did being satisfied with opportunities to be with the dead baby.

Table 1.3 summarises to whom each parent had talked about the death in hospital and the community in the first days after the death and how helpful this had been.

Table 1.3 Bereavement Support from professionals				
Hospital	**N**	**very helpful**	**quite helpful**	**not helpful**
Hospital Doctor	21	21%	58%	21%
Paediatrician	21	62%	29%	9%
Nurse	10	50%	40%	10%
community				
G.P.	48	33%	54%	13%
HV	31	55%	19%	26%
Midwife	10	44%	33%	23%
Social Worker	9	17%	50%	33%
Minister	36	41%	38%	22%
* Taking N from all 67 parents. The % is worked out from those who expressed an opinion.				

In hospital, nearly two thirds of 21 parents perceived the paediatrician as very helpful. However of the 42 sets of parents, less than half had been back to the hospital to talk of the death with a paediatrician. Of those parents who had not done so, nearly half would have liked the opportunity. As nearly half the deaths had been caused by cot death, parents may have wanted more information on why their baby had died.

In Mandell's study (1987) in the Unites States, 36 (77%) of the 47 paediatricians indicated that they were able to discuss the infant's death with the family. However, 11 of them reported that they purposely avoided discussion of parental feelings and six said their discussions had been brief. As Mandell has suggested:

> Professional competence, sincerity and sensitivity during this tragic experience sets the tone for family grieving and the beginning of healing. Despite the necessity of providing this kind of care, formal preparation for death counselling is not a usual part of medical education (Mandell 1987:750).

He sees the paediatrician being the cornerstone of support. However, as he suggests, there are occasions when anxiety prevents practitioners from using the most basic grief

counselling skill, that of listening empathetically as a family begin their grieving. He also suggests that while the paediatrician can be a pivotal person in the initial support network, local additional support services should be known and offered to parents.

In Phase 1, at the first visit after the death , a third of 48 parents found their G.P very helpful and over a half of 31 parents, their health visitors. However, just over a quarter of the parents found their health visitor not at all helpful, which would indicate the health visitors may require more training.

Support for Parents in the Community

It has been stated that generally a single interview with parents and a health professional at the time of their child's death is unsatisfactory and represents incomplete counselling (Williams 1963). This is especially true when the death is sudden and unexpected. Parents can assimilate only a limited amount of information at the time of death and questions and doubts related to the death may arise months later (Friedman 1974).

As can be seen in Table 1.4 the number of families who received on-going support in the year after the death was small.

Table 1.4 Ongoing Support from Community Professionals		
Professional	Number	Percent
G.P	9	13%
Health Visitor	8	12%
Counsellor	3	4%
Psychiatric Nurse	9	13%
Psychologist	1	1%
Social Worker	3	4%

For those who had seen a social worker, (s)he had been involved with the families before the death. Following the first visit after the death, only 13% of families were visited by their G.P., a third of these visits perceived by parents as being very helpful, just over a half as quite helpful and 13% not at all helpful. Likewise only a small number of parents (12%) were visited by their health visitor, although over a half of the parents said how very helpful these visits had been, nearly a fifth perceived them as quite helpful and a quarter said they were not at all helpful. A third of parents said that no professional had helped.

It was apparent from the responses that many parents felt isolated and unsupported. As one father wrote:

> Professionals should get more involved. They should contact the parents afterwards. We could have gone off our heads here. No-one would have known. They should check to make sure parents are handling it O.K.

The following comments made by parents in guiding community professionals, indicated that they would have appreciated more contact and support.

> Always have time to listen. More support is needed at home by the health visitor, not just after the death but afterwards.

> You don't get over the death of your child in a few months.
>
> Never be afraid to show you care. The death of a child is extremely distressing. Be honest and grieve with the parents.

One father commented how hard it was to come to terms with his daughter's death.

> Sometimes I can't talk to anyone, although I try to bring it into conversation. When my partner talks about it, I find it hard to talk back and try to avoid it by going out.

One mother who felt alone and isolated, said:

> I wanted to scream at them: "It isn't catching, it won't happen to you!" Even close friends find it a difficult subject so avoid it (and you). The longer the words are *put off, the harder it becomes, so eventually, it's easier* not to speak at all.

Support from Support groups

Just over a third of parents had made contact with a local bereavement support group, where they turned to other bereaved parents for support. For the 15 parents who had discussed the death with a support group, this had been very helpful for 10 of them. A third of these parents had been told about support groups by hospital staff and a quarter by friends or relatives. A further 18% said they would have liked to have had contact with a bereavement agency, but did not know of their existence. Whilst the Foundation for the Study of Infant Deaths (F.S.I.D.) specifically gives support to parents after cot death, it would appear that there is little else available to parents whose children die from other causes apart from Compassionate Friends, and in some places, CRUSE. These agencies do not function in all areas, and they may not be suitable for all parents.

Whilst in Phase 1, many parents (90%) thought that their partner sometimes or quite often provided emotional support, over a half (55%) reported that there had been a

severe strain on their relationship since the death. This accords with Cornwell's sample of couples with still-born children (1977) where many parents experienced marital problems. Kalnin (1980) also reports marital problems in over 70% of his sample of couples whose children died of leukaemia. In contrast, Dyregrov & Matthieson (1987) found that over one third of 117 couples reported that talking together of the death of their child brought them closer together.

In Phase1, for those couples with other children, there was the added burden of trying to care for them as well as dealing with their own grief. Of the 42 families who responded, 33 had other children, totalling 68 (33 boys and 35 girls), ranging in age from 1 month to 15 years. The parents reported that of these children, 38% had become withdrawn, and a quarter had exhibited aggressive behaviour since the death. Telling fibs, being unable to concentrate, bed-wetting and being bullied were also common. Of the parents, only two sets said they had been given guidance by professionals on helping their children. Nearly three quarters of the parents would have liked more help and information on how to help their children, as well as more general information about bereavement.

It was interesting to note that of those parents who responded, many made comments, unasked for, throughout the questionnaires about their feelings and attitudes. Letters were written in many cases to accompany the questionnaires. As one father said:

> Because one is in a state of shock, you tend not to ask the relevant questions. If you don't ask, you don't get told. People are too afraid of upsetting you further.

Another was surprised that it took two years for the questionnaire to come. All parents except one father, were willing to be contacted again, if further information was required. It could be argued that of those who replied, this may have been the first opportunity of talking of the death in any detail.

Analysis of Responses from Health Professionals

Of the 598 institutions or individuals contacted, the overall response rate was 74%, the highest response coming from hospital chaplains of 93% (n=15) and the lowest from the voluntary agencies of 63% (n=48).This response rate was better than expected and could reflect the concern that many have about this area of care. For the present thesis, the responses of community staff, especially health visitors, are described in some detail, as the focus for improving care in Phase 2 is directed at them.

Responses from Health Visitors

Of the 240 health visitors asked, 186 responded (78%). Of these, nearly half (45%) had been involved with the death of a baby, and a third with the death of a child over two years of age in the two years preceding the study. Despite this, few health visitors knew if there were policies within their health districts for guiding them in caring for families. In most hospitals now, it is current practice to have a written policy on procedures following a death. Some health districts in some parts of the country have developed guidelines to assist and guide health professionals in the community when a child dies, but it would appear that this is not widespread. Just over a third of the health visitors

knew of a policy on caring for families after the death of a baby and only 16% knew of any guidelines for helping them with families whose older children died.

It was important to note that virtually all health visitors (99%) believed that families should be offered follow-up after the death of a child, and agreed that health visitors have an active role to play. Yet there were very few guidelines to help them, despite the fact that over half (58%) had been involved with a child death in the preceding two years. As one health visitor commented:

> I hope this study will enable policies on bereavement care to be part of all health districts, so that a consistent approach, backed with relevant information and appropriate training can enable professionals to offer appropriate support.

Over half the health visitors thought that they needed both information and training in several areas of bereavement care. Three quarters wanted training on bereavement counselling and nearly two thirds training on assessment of families needs in planning care and care of siblings. Of the comments made at the end of the questionnaire, 41% made specific reference to the lack of training given or available. As one health visitor said:

> I think supporting parents who have lost a child is one of the hardest jobs we are expected to do, and one (for)which we are hugely ill-prepared and consequently dread.

Another made the following comment:

> It would be helpful to have multi-disciplinary training sessions on care of the bereaved to include voluntary agencies. This would hopefully forge closer links between the two sectors, as well as clarification of roles to provide a more unified service to parents. Counselling skills are essential for those involved and should form a fundamental part of training.

A newly qualified health visitor wrote:

> I feel ill-equipped to "deal" with bereaved parents/siblings. I look forward to a positive outcome which will ultimately enable us to be more effective in our approach to and support of the bereaved.

The fact that the health visitors demonstrated high levels of need but low levels of training, that they felt they were appropriate professionals to take on a supportive role, would point to the need for more training in this area.

Responses from G.Ps

Of the 240 G.Ps asked, 166 took part in the study (69%). The majority (92%) had received little or no specific training, in how to help a bereaved family. Most had picked up information and guidance as senior officers in paediatrics and in Accident and Emergency Departments. Nearly all (93%) thought training would be useful, some believing that it should be included in medical schools.

One of the most significant findings from G.Ps was the fact that three quarters of them referred families to their health visitor and most G.Ps felt that health visitors were appropriate professionals to offer support to bereaved families. The reason for this may lie in the fact that few had been given any training. Two thirds had referred families to bereavement agencies, just over a quarter to psychiatrists and a fifth to community psychiatric nurses. This is a high referral rate, which could imply that G.Ps do not consider themselves as appropriate for supporting families either because of lack of training or time, and/or that they consider the parents as having needs which warrant psychiatric intervention. It was unknown as to how long after the death these referrals were made.

Conclusions

The above results show a clear distinction in satisfaction between bereaved parents' perceptions of care in hospital and in the community. For many parents, the service given by hospital staff was perceived as good on the whole, an improvement on Finlay & Dallimore's findings in 1991. This study demonstrated that improvements could be made in offering a follow-up appointment to bereaved parents to discuss their child's death with a paediatrician, who may be able to answer some of the parents' medical questions.

One of the most significant findings, was the lack of support in the community for bereaved families, which left parents feeling isolated and unsupported. Whilst some families were able to rely on support from partners, many would have appreciated visits from their G.Ps and health visitors. Of those parents who had surviving children, many had identified behavioural changes in them since the death and would have appreciated advice and guidance in helping them. As has been stated earlier in this thesis, the death of a child is a family affair, where children too may be involved, and the fact that very few parents were given help or guidance by health care professionals is a matter for concern.

The high response rate from health visitors could reflect their need to be given guidance and assistance in an area which requires sensitivity and understanding. Of those health visitors in the study, over a half had experienced the death of a child or baby within the preceding two years and yet within their health districts, few knew of any written district

policies to guide them. Almost all believed that families should be offered follow-up care and that health visitors have an active role in helping bereaved families. However, only a quarter of health visitors had been given specific training on caring for families after the sudden death of a child, and yet nearly all thought this would be helpful, especially on assessing a family's needs, planning care and helping bereaved siblings.

In relation to G.Ps, it is interesting that 69% responded and yet the response rate asking for G.Ps permission to approach bereaved parents in the same health districts was extremely poor. It is likely that of the respondents picked randomly, some may have been the G.Ps of bereaved parents in the study sample. The relatively high response rate of the G.Ps in answering the questionnaires might imply that the strength of the questionnaire lay in its anonymity when highlighting their inexperience and lack of training in the area. It was established that very few had received training and like the health visitors, most would find it useful. It could therefore be suggested that this is the reason why three quarters of G.Ps referred bereaved families to health visitors, believing health visitors were more appropriate professionals to support families.

From the children identified in the present study, the mean number of children dying suddenly and unexpectedly was 9 per annum in each health district ranging from 3 to 17. Although the number of children who die is small, it does not reflect the number of people affected by the death. There are no statistics which indicate the numbers who will grieve and yet it can be assumed that there will likely be two parents, possibly four grand-parents and an unknown number of grieving siblings. As has been recognised in

earlier chapters, the death of a child is a highly stressful event, affecting all in the close family. The sudden, unexpected nature of the death and that of a child, puts family members into a high risk group for experiencing a difficult bereavement process and therefore it would seem appropriate to consider ways in which family members can be helped and supported from soon after the death. The first level of help is the natural support system, families and communities, and some in this study showed that they received this. However, for many, they felt lonely and isolated. As Silverman has suggested:

> People need concrete assistance; they need support over time, and they need people who can listen and recognise their needs.....No individual or family should have to deal with a death and their subsequent grief alone (Silverman 1996:354).

In the light of the findings from Phase 1, it would seem appropriate, therefore, to focus further research on improving community care for families whose children die suddenly and unexpectedly. As health visitors and G.Ps both believe that health visitors have an appropriate role in supporting bereaved families, and bereaved parents would value more support from members of the primary care team, health visitors would seem to be key professionals in changing the current support situation. The next chapter will consider possible ways of achieving this.

CHAPTER 8

THE DEVELOPMENT OF AN INTERVENTION FOR BEREAVED FAMILIES

Introduction

The first phase of the research, reported in the last chapter, established that the majority of parents who had suffered the sudden, unexpected death of their child felt isolated and would have appreciated more visits from members of their primary health care team. As a consequence of these results, it seemed appropriate, therefore, to consider ways to implement change, so that bereaved families would feel better supported and less isolated.

The emergence of voluntary bereavement agencies began in the 1960s and has continued to grow; but it cannot be assumed that those grieving for the death of their child will have access to such agencies or that they will be suitable for all. As Phase 1 showed, many parents felt isolated and unsupported, although voluntary bereavement agencies were functioning in the targeted areas.

Whilst the highest response rate in Phase 1 came from hospital chaplains, which would suggest that they were interested and concerned about support, their role is hospital-based, so giving on-going support to families in the months after a child death, is not a role that they could easily take on.

Only 13% of G.Ps had followed up the bereaved families in Phase 1 possibly because. few had been given any training and may therefore have lacked confidence to visit. This may have been the reason that they believed health visitors were more suitable to offer support to families. Health visitors also in Phase 1, believed that they were appropriate

professionals to support such families, but felt unable to offer support due to lack of training and expertise. It would seem relevant, therefore, to seek ways to assist health authorities in empowering health visitors to feel more confident in continuing to visit.

The Role of the Health Visitor in the Health Service

The role of health visitors in preventive medicine dates back to the nineteenth century when they were employed to act as "lady visitors" to teach mothers elementary hygiene and methods of infant care and management (Stacey 1988). By 1927, they were sufficiently professional to have achieved occupational closure in the sense that only a state registered nurse could qualify (Davies, 1983). The responsibilities of the health visitor were defined in 1974 by the DHSS as consisting of: giving health education and advice to all families or individuals she visits in the home, the doctor's surgery or the health centre; having a regard for the medical, psychological and social needs of the whole family and being aware of help available or given by other workers; having a readiness to take account of psychological factors in every case with which she deals, being constantly aware of her role in the promotion of mental health and the prevention of mental illness; and finally, offering comprehensive counselling services to families in need, and in seeking appropriate help from other agencies.

As discussed in previous chapters, when a family experiences the death of their child, family members may suffer severe stress, may be more prone to mental and physical ill health and may require counselling. The responsibilities of the health visitors outlined above cover such areas and thus health visitors would seem ideal professionals to take on a supportive role of families when a child dies suddenly. However, as yet, whilst it may be implicit that health visitors fulfil this role, no government guidelines have made explicit that bereavement care of families is an area of responsibility for the Health Service. Averill & Nunley (1993:77) have suggested that grief is increasingly being

recognised as a "problem to be treated within the health care system." However, they do not state how this can be achieved or which group of professionals should take on this responsibility. As Averill and Nunley are both psychologists, it could be assumed that they mean their profession or psychiatrists, who function within the health service, and thus may pathologise grief. In contrast, it can be assumed that grief is not a "problem", but rather a normal reaction to the death of a significant person. For some, dealing with the reactions of the death may be difficult, for others they will recover without intervention. It is the identification of those needing more help from soon after the death that requires attention, so that future referral may be avoided or minimised. Although health visitors are nurses trained essentially in the medical model, they also have skills in assessing needs of families. Many families may be known to them from before the death, so it would seem appropriate that they are key workers in the health service, for identifying needs and offering support.

Home Visitation of Bereaved Families

Home visitation has recently been suggested as a means to effectively reach families with many problems; for example: low birth weight, child abuse and neglect, adolescent pregnancy, respite care, and follow-up of bereaved people after the death of a relative from terminal illness (Gaines, 1996). One of the few studies conducted on employing nurses for supporting families after a child death, took place in New York (Gaines, 1996). She looked at the feasibility of home visiting by public health nurses, (the equivalent of health visitors) for families who had suffered cot death. Of 40 identified families, only 18 (45%) accepted home visits. It took an average of six phone calls to each family before the visit was either accepted or refused. Although only a small study, this research found that parents and nurses viewed the home visit as positive and supportive. The nurses believed that they had been able to help parents modify their feelings of guilt and refer to others when necessary. The nurses involved were not

known to the families before the death which may have accounted for the poor response. In contrast, health visitors in the U.K. are generally known to families which could make a significant difference.

This chapter, therefore, considers possibilities available to health authorities to improve support for bereaved families by targeting health visitors. Of these approaches, the development of an intervention, providing a framework for them to plan care, based on identification of stresses within the intra, inter and extra personal dimensions encompassing a bereaved family was devised. As health visitors are nurses trained essentially in the medical model, the intervention was based on a psycho-social approach which would seem more appropriate for those bereaved. This forms the major part of the research and will be discussed in detail in this chapter.

Possible Ways for Health Authorities to Improve Bereavement Care

Using the results from Phase 1, four main areas were identified which could effect change in support of bereaved families- extensive training programmes for health visitors, the introduction of a bereavement resource person for health visitors involved with child death, relevant and well known policies to guide health visitors and finally the development of an intervention to encourage health visitors to visit by giving them an assessment tool from which to plan family care and a booklet giving information about bereavement. Each of these possibilities will be discussed.

Extensive Training

For health authorities to provide more training courses for health visitors, would appear to be the most obvious solution. With this in mind, an extensive training programme for health visitors in all the health authorities of the South & West region was considered.

However, this was rejected for several reasons. The average number of child deaths in Phase 1 was shown to be only nine each year in each health district, so that the number of deaths that any one health visitor would experience in his/her working life is likely to be small, if at all. For this reason, many of the health visitors who attended a training course may have no need to use the principles or may have to wait a number of years before they were called upon to use them, by which time recall may be difficult. Furthermore, there was no guarantee that funding would be available within health authorities or from other health service sources, to carry out such a project.

Resource Person

If bereavement care of families is to be incorporated into the health service, the sudden death of a child inevitably means that health visitors will be required to visit without previous warning and more than likely, without any training. This may seem a daunting task for the health visitors, especially if there is no professional to whom they can turn for advice and guidance. In other areas within the health service, nurse specialists have been appointed to help generalists. For example, the introduction of Macmillan nurses in cancer and palliative care has been shown to have been of great value to both patients and health care professionals (Saunders, 1996:317). Such nurses work alongside G.Ps and district nurses, being available to offer advice, guidance and support when required. It would seem, therefore, appropriate to provide a similar resource for health visitors dealing with bereaved families. Whilst it may be implicit that health visitors within the health service are involved with bereaved families, there is no explicit guidance from the Department of Health that this should be part of their role. Therefore it may be unlikely at the present, especially given the financial constraints within the health service, that providing such human resources for health visitors, will be given priority.

The Development of Policies within Health Authorities

The results from Phase 1, in the last Chapter, demonstrated that few health visitors knew of policies within their health authorities which would guide and assist them in dealing with the sudden death of a child. This would, therefore, appear to be an area which requires some attention. The recent report submitted by the Public Health Alliance (1998) suggests that for many areas of health, national frameworks should be developed to give health authorities key pointers in constructing their own policies. If bereavement care moves into the health care sector, it is suggested that such a framework should be made available to all health authorities. It is further recommended in the above report that in developing a strategy, not only professionals but also lay people should be involved in its preparation. This would seem an excellent opportunity for professionals and lay people, especially for those who have experienced the death of a child, and for those in the bereavement voluntary sector, to work together to create a meaningful and appropriate policy. In the first instance, this would necessitate a small group of experienced and relevant people meeting together under the aegis of the Department of Health, to form a framework for a national policy to guide health authorities in developing their own policy. Such a move would make explicit that bereavement care of families was seen to be part of the health service which encourages collaboration with other agencies to bring about change.

Whilst bereavement training and the introduction of bereavement resource professionals is largely dependent on financial resources and therefore may be unrealistic at the present, the introduction of polices within health authorities may be more easily attainable. However, the development of a national framework to guide health authorities may take some time. For this reason, a fourth option was considered, that of introducing an intervention for health visitors to use with bereaved families.

Reasons for Developing an Intervention for Health Visitors

Health visitors in Phase 1 demonstrated that more training would help them to feel more confident to visit. We have already seen that to run extensive training programmes would be costly and may not be relevant to all. As part of training is imparting knowledge, knowledge would seem to be a key element in encouraging health visitors to visit bereaved families. Up until recently bereavement care has not been viewed as part of community care. It is not surprising, therefore, that a framework for bringing together all the elements of recent bereavement research has not been devised for community health professionals within the health service. Consequently, no systematic approach has been designed to determine those who are able to recover with minimal or no help, those likely to have a more difficult route to recovery and may require more support or even specialist intervention; nor would it appear that there is any method to guide health visitors in determining the frequency of visits, the number of visits or the length of time required to help those families in need of support. Without such a framework, it is not surprising that professionals may feel overwhelmed, not only by the pain and suffering of family members, and possibly their own sadness, but also by the multi-faceted aspects of bereavement which encompass a family. It would seem difficult to know how best to help without first identifying the unique stresses that any one family may be experiencing, so that a care plan can be constructed, with a view to reducing stresses where possible.

Stewart (1993) suggests that health visitors should visit a bereaved family within the first week after a sudden child death, so consequently there will be little time for them to gain information, if necessary, on bereavement care. Furthermore, if such information is available to them, they may be overwhelmed by the extent of theory presented in many of the books. As we have seen, bereavement is a

complex subject.

A Psycho-social Model

Taylor, Peckham & Turton (1998) suggest that the medical model underpins current definitions of primary care and inhibits the development of community perspectives on health. Primary care, it would seem, continues to be viewed as primary medical care (Peckham et al, 1996), which emphasises illness and medically defined solutions to health needs.

Although bereavement can affect a whole person, that is physically, mentally and socially, it is not an illness as such (Averill & Nunley, 1993). Therefore, as health visitors are all nurses trained in the medical model, it would seem appropriate to develop a different model to guide them into a more psycho-social approach when caring for bereaved families.

The White Paper, "The New NHS" (DOH, 1997) and the Green Paper "Our Healthier Nation" (DOH, 1998) represent the latest efforts to develop the NHS and indicate structures in primary care, as yet bereavement care does not feature specifically.

However, the Public Health Alliance (1998) has suggested a new approach to thinking of primary care, defined as the "public health" model, drawing on the World Health Organisation's (WHO) definition of primary care (Alma Ata, 1979), and making several conceptual and practical additions to the medical model. This widens the concept of health from that of "absence of disease" to that of the WHO definition of positive health, that of a state of physical, mental and social health. Bereavement may affect all three areas of health. Therefore the aim in helping the bereaved is to maintain or attain health in all aspects, which matches with the public health model. A

bereavement assessment tool, based on holistic care, would thus guide health visitors into a wider model than the medical one.

A Stress Model

The pioneering work of Seyle (1956) showed that life change creates disequilibrium, which imposes a period of readjustment and which can leave a person more vulnerable to stress and its deleterious consequences. Although only a few studies in recent years have looked at physical and mental health problems following stress exposure, there would appear to be a relationship between stressful life events and subsequent health (Rabkin & Struening, 1976; Thoits, 1983; Stroebe & Stroebe,1993).

The loss of a loved one through death is considered the most stressful of all life events (Holmes & Rahe, 1967), with significant readjustment necessary for adaptation following the death (Brown & Harris, 1989). Continued stress may precipitate the onset of physical or mental illness, particularly if a predisposition toward that disorder already exists. The first of these is a direct effect through the brain's influence on physiological responses to psycho-social influences. For example, it has been suggested that stressful life events can impair immune function and increase susceptibility to infectious diseases and increase cancer risk (Kim & Jacobs, 1993; Laudenslager, 1993). Stress has also been shown to result in endocrine changes that contribute to heart disease (O'Leary, 1990; Stroebe & Stroebe, 1987). The second mechanism involves an indirect effect, whereby stressful life events result in health-impairing behaviour patterns such as cigarette smoking, excessive alcohol consumption and irregular and unhealthy eating patterns (Stroebe & Stroebe, 1987).

The possible stresses involved in a family after the sudden death of a child, have been

detailed in Chapters 3, 4 and 5, where it was shown that there are three main areas which may give rise to stress, namely the intra-personal, the inter-personal and the extra-personal. In constructing an assessment tool, it was necessary to include all three aspects, so that after identification, alleviation or amelioration of these stresses may start as soon as possible. Stroebe and Stroebe (1993) suggest that the first few weeks and months are the most critical for bereaved people, thus in developing an intervention which allows health visitors to identify stresses in the different variables from soon after a death, they are guided to ameliorate or reduce them at future visits, which may lessen the possibility of ill health at a later date.

Thus the intervention serves three purposes. Firstly, by giving health visitors a structure from which to base their care, they may be encouraged to continue to visit, thereby lessening the possibility of families feeling poorly supported and less isolated. Secondly, in working with families to reduce stresses, health visitors may prevent future illness. Thirdly, bereaved parents, in working with their health visitors, may feel more in control and more aware of which areas they have particular difficulty. It has been suggested by some researchers in the field that family members should be assisted to help themselves (Hopson and Scally, 1977; Worden, 1983; Montgomery, 1993). The professional's role is therefore, not to "do" for them but to empower the bereaved to help themselves. This can only be achieved by first empowering professionals in giving them some understanding of bereavement, and a framework to work with.

A Bereavement Assessment Tool

A bereavement assessment tool was designed with the specific aim of identifying stresses in three areas, thus there were three main sections. Firstly, section 1 considers the intra-personal aspect, as discussed in Chapter 3, involving possible emotional, physical and spiritual stresses within individuals which may have arisen as a result of

the death. Secondly, section 2 considers the inter- personal aspect, that is stresses which arise from difficulties with or changed family relationships as a result of the death, as was mentioned in Chapter 4. Thirdly, section 3 focuses on the social or extra personal aspect, that is, identifying stresses arising from external influences such as friends, neighbours, less close family members and professionals as discussed in Chapter 5.

Within these three sections, 20 areas were identified which could give rise to stress (Appendix 2). The tool, therefore, was divided into 20 sections, with suggested questions in some of the less obvious sections to guide the health visitor when necessary. Under each heading was a space for the health visitor's comments. Each of these sections will be discussed in detail.

Section 1

The Intra-personal Aspect

This section considers the physical, psychological and spiritual aspects of the parents. Where only one parent is seen, the intra-personal stresses of other family members may become apparent when talking of the inter-personal stresses.

Asking About the Death

By guiding health visitors to ask about a death, clear messages are conveyed to bereaved parents that their health visitor is willing to talk of it, is interested, and sees it of great importance to the parent(s) (Raphael,1983:362). It provides an opportunity of gaining information about the parents' reactions to the circumstances surrounding the death, and how they perceived the care given by medical and emergency personnel. Raphael (1984) suggests that the bereaved's capacity to talk of the death and their pattern of emotional responsiveness about it, may highlight anger, helplessness, and/or guilt. Defences of denial and avoidance may also be evident.

After the Death, Information and Follow-up

In discussion with the parents, the manner in which they were treated by hospital staff after the death, may identify anger, resentment, or gratitude. Phase 1 showed that many bereaved parents would have appreciated more choices in hospital such as staying with their child for as long as they wanted, washing, dressing him/her, being given foot-prints, hand prints, and photographs of the dead child. It also is an opportunity of finding out what information the parents were given by the hospital and whether a follow-up appointment had been arranged.

Post-mortem and Coroner

In all cases of cot death, and other deaths where there is no obvious cause, the coroner's office (police) will be involved. If they or their child's body was not dealt with sensitively, the parents may feel angry and upset. Where the coroner is involved, a post-mortem will follow by law. Parents should have been asked if they wanted to know what the post-mortem examination entailed. Hindmarch (1993) suggests that many parents do not like to ask, but are later filled with remorse for not knowing and may suffer from fantasies of butchery. In Phase 1, just over a fifth of the bereaved parents whose children underwent a post-mortem, did not understand the findings, 13% had not been allowed to ask questions and over a quarter did not understand the answers to their questions. For those that had received insufficient information, there remained many doubts and confusion. If this is the case, then health visitors may be able to arrange for the G.P or a paediatrician to clarify the situation.

The Funeral

In discussing the funeral, the bereaved parents' acceptance of, involvement with and feelings about it may become apparent. Parents may have been rushed into making hasty decisions about funeral arrangements which later cause regret and anguish (Hindmarch,

1993). It can also be established if any financial difficulties, arising from the funeral and other related expenses (such as an expensive tomb-stone) are causing concern.

The Spiritual Aspect- The Meaning of Life/Death

This was discussed at some length in Chapter Three. It forms an important aspect of the grieving process and therefore has been included in the bereavement assessment tool.

The Media

Whilst there is no mention of media invasion in the literature, in Phase 1, it was found that of 42 cases of sudden child death, *25 (60%) had been given local media coverage.* Nearly two thirds of these parents felt angry and dissatisfied with the press because of their constant harassing and because reports had given wrong information. By including a question on this subject, an opportunity is given to the parents to verbalise their feelings.

Physical Health

The physical sensations associated with grief include hollowness or tightness, (hollowness being associated with the stomach or abdomen and tightness with the chest, shoulders and throat), over sensitivity to noise, breathlessness which is often accompanied by deep sighing respirations, muscular weakness, lack of energy and fatigue and a dry mouth (Littlewood, 1992:41). Although the physical sensations may be frightening, they are not in themselves cause for concern. However, a health visitor may be able to reassure bereaved parents that what they are experiencing is a normal reaction to a severe shock and symptoms will abate in time. Whilst loss of appetite and sleep difficulties are common (Worden, 1983), continued anorexia and insomnia may lead to impaired immune function (Laudenslager, Boccia & Reite, 1993; Kim & Jacobs, 1993). Suggestions may be necessary to encourage sleep and appetite to protect the immune

system. Reduction of other stresses may help to alleviate the situation.

Past Losses

Evidence is ambivalent about past losses; previous bereavements may be of benefit if successfully negotiated. However, people who have experienced complicated grief reactions in the past will have a higher probability of having a complicated reaction in the present (Worden, 1983). As Simos suggests:

> Past losses and separations have an impact on current losses, separations and attachments and all these factors bear on fear of future loss and separations and capacity to make future attachments (Simos, 1979:27).

Thus in asking about past losses, health visitors are in a better position to identify those who may need more help with a previous bereavement or arrange a suitable referral if they believe the situation is too complex.

Section 2

The Inter-personal Aspect:

Relationships with Others in the close Family

The Parents

Research has shown that following a child's death, parents may have difficulty in communicating with each other (Dyregrov & Matthiesen, 1987; Littlewood & Cramer, 1991). Differences in grieving between the parents may result in frustration, misunderstanding and further isolation (Schwab, 1992). As Hindmarch suggests (1993), effects on the marriage or partnership following the death of a child, will depend largely on the strength of the couple's relationship beforehand. Any needs that are not being met will be magnified by the loss and may cause resentment. Initially a reasonably open and trusting relationship allows the parents to comfort each other, although as time goes on even the closest couples find that grief separates them in some way. Two people

cannot grieve at the same pace nor tend to each other's needs without sacrificing their own (Hindmarch, 1993). In Phase 1, 55% of parents said they had experienced a strain in their relationship with their partner since the death.

Many studies (Cornwell, 1977; Defrain & Ernst, 1978, Jurk et al, 1981; Kalnins et al, 1989, Rando, 1991; Fickling, 1993) call for an improvement in long- term professional care and better understanding in medical and other services of the immensity of the challenges that face bereaved parents.

Relationships with surviving Children

Worden (1996) has demonstrated that children grieve and may show a wide range of so called "disturbed" reactions to a significant death. Parents will have their own grief to deal with as well as that of their surviving children. At any age, a child will be affected by the parents' distress and made anxious by upheaval in the home and family. Hindmarch (1993) suggests that it is essential for bereaved children to see their parents mourn, or they will believe that the dead child was not loved and fear that they would not be mourned either if they were to die. Phase 1 showed that of 33 sets of parents who had surviving children, three quarters had noticed behavioural changes in their children since the death. The majority reported that they had no-one to ask for guidance and help in assisting their children, so it could be assumed that in dealing with their own grief, as well as dealing with their children's reactions, they may have been under considerable pressure.

Relationships with Grandparents

Raphael (1984:274) has suggested that mothers may be disappointed in their own mothers for their failure to understand and offer emotional assistance. As was noted in Chapter 4, the grief of grandparents is often neglected, compounded by the fact that

norms for talking of death are changing, so different generations may no longer know how to communicate with each other about the death. In relation to the surviving children, there may also be tensions between the dead child's parents and their own parents on whether the children should be involved in such rituals as the funeral, or even whether they should be given details of the death.

Section 3

The Extra-personal Aspect

It is suggested that parents whose child has died gain a stigmatized status (Riches & Dawson, 1996). The family which suffers the death of a child may be left isolated since friends and neighbours may feel insecure about how to behave or what to say (Thuen, 1997). According to Wortman & Lehman (1985), the most obvious supporters may experience intense anxiety about the prospect of interacting with a person who has experienced a life crisis like bereavement. The death of a child, a rare event, may cause even greater anxiety.

Chapter 5 demonstrated that social support was an important factor in helping the bereaved to recover. By including a question about the reactions and involvement of friends and neighbours, the pattern of their responses since the death and the quality of the social network perceived to be available to the parents, will be ascertained. A health visitor may suggest ways in which neighbours and friends may be able to help with any practical difficulties arising from the death, such as taking the other children to school initially if a mother feels unable to face other parents, doing shopping or child minding. At the same time, such a line of inquiry provides a clear indication to the bereaved of the importance of his/her feelings about relationships outside the family.

Fears and Strengths of Family Members

At the end of the assessment tool, a space was provided for health visitors to ask parents about any fears they may have which were not included in the other sections. A space was also left for health visitors to discuss parents' strengths, with the aim of giving the parents an opportunity to consider their personal resources in dealing with the tragedy.

Having established from the parents, a picture of the various stresses on the family, health visitors were asked to prioritise them and to confirm with the parents the accuracy of their assessment. From there, future care is planned by the health visitor and the parents, and assessed at each visit thereafter.

Booklets for Health Visitors and Bereaved Parents

To assist the health visitors in using the assessment tool, a booklet was also designed to give them more information on why the different sections had been included. Incorporated into the booklet were the main principles of Parkes (1975), Worden (1983), Rando (1991), Raphael (1984) and others, with specific reference to the "tasks" of bereavement suggested by Worden (1983). A section was included on care for the health visitor. A list of suggested further reading, national bereavement organisations and available leaflets was also included.

Littlewood (1983) suggests that the bereaved need information, which was reinforced by the findings in Phase 1. It, therefore, seemed relevant to provide an information booklet for bereaved parents. Many may be experiencing bereavement for the first time, and so may be unaware of the nature of grief, its intensity and its length. Parents may not always recognise that others affected in the family may grieve differently and at different times. The Stillbirth and Neonatal Death Society and the Foundation for the Study of Infant Deaths both produce excellent leaflets for parents. The Compassionate

Friends also has a wide range of leaflets suitable for any child death, but parents may not come in contact with them until some months after the death, if at all, as Phase 1 showed. As in the health visitors' booklet, a list of books, national bereavement organisations and leaflets was also included.

Summary

In summary of this chapter, the intervention consists of a bereavement assessment tool and two information booklets, one for health visitors caring for the bereaved family, and one for bereaved parents. The development of the bereavement assessment tool was based on the need to give information and a psycho-social framework to health visitors so that they would be assisted in planning future care and thereby encouraged to continue to visit. The basis of the tool was in identification of stressors within the intra, inter and extra personal dimensions with the aim of reducing stressors wherever possible to prevent possible future illness. It followed the lines of the stress prevention model and stress buffering model discussed in Chapter 5.

Having designed the intervention, the next stage was to test its efficacy, both in relation to how useful it was for health visitors and whether in using it, bereaved families felt better supported. The following two chapters give the results of the study.

CHAPTER 9

PHASE 2: BEREAVED PARENTS' PERCEPTIONS OF SUPPORT

Introduction

The last Chapter examined in detail the development of an intervention for bereaved families. To test its efficacy, a randomised trial was conducted in the South & West region over a two year study period, the main hypothesis being that where it was used, families would receive better support from their health visitors. The methodology and methods for conducting this trial are discussed in Chapter 6.

The first part of this chapter will consider any differences between the two groups of parents which might have biased the results of the assessment tool. Secondly, using the responses from the parents, it will consider differences that the assessment tool may have made in identification of stresses by the health visitors, which may have arisen from the intra, inter and extra personal aspects of the family's bereavement. This will lead on to looking at whether the assessment tool made any difference to the planning of care and support for the study parents and contrasted with those parents in the control group where the intervention was not introduced. The final part of the chapter will consider other findings from the study relevant to bereaved parents.

Chapter 10 then goes on to consider the responses of the health visitors in both the study and control groups to determine any differences that the intervention may have made to the study health visitors in caring for their recently bereaved families.

Deaths reported over the Study Period

Without the help of the existing CESDI network (Confidential Enquiry into Sudden Deaths in Infancy), and hospital and ambulance personnel throughout the region, this study could not have been undertaken, as I relied heavily on their reporting of deaths. During the two year study period 184 deaths from sudden, unexpected causes were reported, 101 (59%) from the study group and 83 (41%) from the control group. In each health district the number of deaths varied from 2 to 19, the mean number being 7 over two years.

Exclusions from the Study

Of the184 reported deaths, five families (2%) did not reside in the study area, although the deaths had taken place within the region. They were excluded as any health visiting involvement would be outside the area of the study. A further twelve families (8%) were excluded from the outset as the deaths were a result of non-accidental injury or manslaughter. Whilst it is recognised that such families may have acute needs, health professionals tend not to get involved because of legal implications. Thus health visitors may not have been involved with the families in the study. However, it does raise the question of who offers support, especially to those in the close family who have not caused the death. Hindmarch (1993) suggests that where murder of a child is suspected, there may be an element of social stigma, making such deaths difficult to talk about, thus reducing the level of sympathetic support more likely to be forthcoming in other situations. Bereaved families are therefore likely to be further isolated. She also suggests that the legal system may take over in such a way that leaves the family doubly

victimised. The literature search found a paucity of information on the subject, so it could be suggested that little attention has been paid to this group of families, who may have considerable social problems stemming from before the death, and who may need much support through the agonising months before and after court proceedings.

As a result of exclusions by study design, 167 families remained in the study. Of these families, 18 (11%) were known to have moved since the death, A further 16 (10%) families who received the introductory letter about the research study replied that they did not want to receive questionnaires, and in 11 cases (7%), G.Ps and/ or their health visitors believed that families would be unable to cope with questionnaires. This was respected. As a result of these further exclusions, 122 families remained in the study, 58 (48%) from the study group and 64 (52%)from the control group.

Responses from Parents

Of these 122 families, responses came from 72 families: 34 of the 58 families (59%) who had been allocated to the study group and 38 of the 64 families (59%) allocated to the control group, giving an overall response rate of 59%. This is in line with similar studies, as was detailed in Chapter 7. However, it should be noted that a study by Keeping (1989) suggested that non-participants are likely to have more psychological problems. Vance (1991) also found, in his study on parental responses to different types of infant death, that those who participated were more likely to come from stable, middle- class back-grounds. Hence the data in this study are likely to represent a conservative estimate of what is happening in the bereaved parent population at large.

Most responses came from mothers which reinforces Riches and Dawson's findings (1996), where mothers' willingness to talk about painful events and personal experiences contrasts with fathers' greater reticence. Table 2.1 shows from whom the replies came in this study.

Table 2.1 Responses from Parents

	Study Families (n=34)	Control Families (n 38)
from both parents	18	22
from mothers only	16	13
from fathers only	0	3

The data analysed in Phase 2 have been taken from one parent per family as the focus of support is essentially for the family unit. Males and females may experience different levels of support received from friends, family and professionals although, according to Thuen (1997), a correlation may be found between mothers' and fathers' support as partners are likely to influence each other. As more mothers than fathers replied in both groups, the data from the mothers' questionnaires have been used, except where the father only replied. In the study group, this has resulted in data from 31 mothers, 2 fathers and one foster father. In the control group, the data has come from 34 mothers, 3 fathers and one step- father. It was noted that replies came from 5 single parents, two mothers and three fathers.

Gender, Age and Cause of Death of Children who died

The details of the children who died in the study sample are shown in Table 2.2 and contrasted with the study base. The ages of these children ranged from one week to 12 years.

Table 2.2 Gender, Age & Cause of Death of Children in Study			
	Study Sample (n=72)		Study Base (n=167)
	Study	Control	
boys	25	23	112
girls	9	15	55
under 1 year	22	25	103
1-2 years	3	4	18
over 2 years	9	9	46
cot death	12	17	65
from illness	16	16	74
from accident	6	5	28

In the study sample, the gender, age and cause of death matches the overall pattern of the total group of 167 deaths. More deaths overall (5%) were caused by illness than cot death whereas in Phase 1, 7% more deaths were from cot death than illness. This may reflect the continued decrease in cot deaths.

Overall, two thirds were boys and one third girls. Of the children in the sample, 13% more boys than girls died in the study group and 13% more girls than boys in the control group. Using the Fisher's Exact Test, the gender is not significantly different in each group or from the overall group. According to recent mortality figures (OPCS, 1991, 1996), more boys than girls die each year, especially under one year of age from cot death, and between 15 and 19 years, when accidents are the most likely cause. In Phase 2, two thirds of the children died under one year of age.

In order to set the study in context, and to determine any significant differences between the two groups, which might have influenced the intervention, the study sample of parents were asked to give details about themselves.

Demographic Details of the Parents in Phase 2

Age of Parents

The median age of the study parents was 29 years, ranging from 15-39 years while in the control group the median age was 31 years, ranging from 18-50 years. The majority of parents were living together as shown in Table 2.3.

Status of Parents

Table 2.3 ***Parents' Status***

	Study (n=34)	Control (n=38)
married	23	21
living with partner	5	9
single	4	5
divorced	2	1
widowed	0	2

Around a fifth of all the parents in the study reported that they were without partners: four mothers and two fathers in the study group, and three fathers and five mothers in the control group. As a result of road traffic accidents, two fathers in the control group had also suffered the death of their wives at the same time as their child. The literature search revealed nothing on single bereaved fathers, and a paucity of information on single bereaved mothers. Ostfield et al (1993) suggest that single women whose children have died from a cot death, are at the greatest emotional risk, compared with parents

with partners, of experiencing higher levels of grief and reporting fewer support systems.

Employment of Parents

In the study group, around a half of the mothers reported that they were employed in a wide range of jobs and professions; a third described themselves as housewives. Of the control mothers, nearly two thirds said they were also in a wide range of jobs; as in the study group, just under a third described themselves as housewives. To establish whether there were any differences in employment between the two groups of fathers, data from the fathers' questionnaires was also analysed. The findings showed that only two fathers in the study group and one in the control group, were unemployed at the time of the study. These findings would seem to be in accordance with Keeping (1989) and Vance (1991) mentioned earlier, where non-response families are more likely to be more deprived and from lower classes.

Bereaved Siblings

In relation to other children in the family, the study group had a greater number of siblings as is shown in Table 2.4.

Table 2.4 Details of Surviving Children

	Study	Control
no of other children	48	34
boys	25	18
girls	23	16
under 2 years	3	2
over 2 years	45	32

Nearly all bereaved children in both groups were over two years of age. For nine study families and 12 control families, the child that died was their only child. Effects on the parenting role will obviously be dramatic when an only child dies. In the eyes of society, they are no longer parents, no longer a family (Hindmarch, 1993). The direct line of genetic descent has come to an end. Where there are other children, parental grief is likely to be inhibited and tempered by their needs, which may cause resentment or relief. When the surviving children are young, mothers in particular may not have space and time to themselves to grieve or alternatively, parents who can only think of the dead child may have little interest in the other children (Hindmarch, 1993).

Health of Parents

In contrasting the parents' health before the death again there were no significant differences between the groups. In the year before the death, the median number of days that study parents felt unwell was three days ranging from 0-28 days. In the control group this was four days, ranging from 0-56 days. In the six months after the death, the median number of days taken off work in the study group was four days, ranging from 0-90 days. In the control group, the median number of days was 13 days, ranging from 0-120 days. The reason why more control parents took time off from work is not known. It could be suggested that their employers were more sympathetic to the parents' needs and so allowed more time out, or that the study parents felt less need to stop work because they were better supported by their families and health visitors.

Ethnicity of Parents

With regard to ethnicity, all parents in both groups stated that they were white. Thus, as there were no parents from ethnic backgrounds, the study can only reflect the attitudes of white parents. This is unfortunate as we have no means of knowing what support is offered to ethnic families. As Rosenblatt (1993) points out, professionals' perspectives might seriously violate the norms of bereaved peoples' culture, be out of touch with what is common in their grief process, or be insensitive to the feelings and needs of the mourners, unless professionals share the same cultural background and ethnicity. The bereaved may be pushed toward meanings that do not make sense, to difficulty with people whose support is important, or to intolerable levels of pain.

Thus it can be seen that in terms of gender, age and cause of death of the children who died, there were no significant differences between the two groups. In relation to details of the parents in the two groups there were few differences in age, status, employment and ethnicity which could have affected the evaluation of the assessment tool. However, parents in the study group had 18% more surviving children than in the control group, and more control parents took days off sick from work. These would seem to be the only differences. In relation to *their health visitors' visiting soon* after the death, were there any differences reported by the parents?

Parents' Contact with Health Visitors before and after Death

The parents were asked if they had had contact with their health visitor before the death, whether their health visitor visited after the death and whether they had found it easier to

talk to her about the death because of previous contact. The parent' replies are shown in Table 2.5.

Table 2.5 Parents' Contact with Health Visitor pre & post Death		
	Study	Control
contact with HV pre death	25/29	29/31
contact with HV post death	28/34	31/37
previous contact making it easier to talk of death	18/24	23/29

Slightly more control parents had had contact with their health visitor before the death, and approximately the same in each group after the death. Fewer parents in both groups answered the question on whether previous contact made it easier to talk of the death. However, of those that did, overall of 53 families, 42 (77%) had found it easier. This is an important finding as it demonstrates *that the majority of bereaved parents value talking of their child's death to someone who is already known to them*

Health Visitors' First Contact with Families following the Death

The parents were asked how long it took for their health visitor to make contact with them following the death. Table 2.6 shows their responses.

Table 2.6 Health Visitors First Contact with Families after the Death		
	Study (n=34)	Control (n=38)
visited on the same day	3	4
within the first week	*16*	*20*
within the first month	6	5

The majority of health visitors in both groups had visited within the first week. For those that took a month to visit, it was found that these families had moved away soon after the death to stay with friends which would explain the delay in health visitors making contact.

Having established that the majority of parents reported that their health visitors had visited soon after the death, did the assessment tool encourage more study health visitors to continue to visit, and to identify stresses?

Evaluating the Assessment Tool

As we have seen in previous chapters, bereavement affects a whole person, that is physically, mentally, spiritually and socially. The intervention, therefore, was designed to give an holistic framework to guide health visitors in identifying any particular stresses within an individual, within the close family network, and outside this close circle, from other people. It offered headings and suggested questions to guide the health visitors. Because the information gained in the use of the assessment tool related to the individual families and was therefore confidential, it was not included as part of the research project.

Parents' Responses as to whether they had been asked about Stresses

Identification of Intra-personal Stresses

Intra-personal stresses are those which arise from individuals' reactions to a death. As was noted in the last Chapter, poor past and present physical and mental health may cause a more difficult and prolonged bereavement. Past losses which may not have been grieved for, may also hinder grieving for the present loss. In order to establish whether health visitors had identified particular stresses in any of the above areas, the parents were asked in the questionnaire to give details about health visitors' enquiries. The parents' responses are shown in Table 2.7

Table 2.7 Parents asked by health visitors about Present & Past health, Spiritual needs and Past Losses		
	Study	Control
present physical health	22/26	20/30
past physical health	7/24	11/29
present emotional state	22/24	22/29
past emotional state	8/23	8/26
present spiritual needs	7/25	6/25
deaths experienced in the past	7/21	9/29

Although slightly more study health visitors had asked about the various aspects, the results are remarkably similar in both groups. It would, therefore, appear that the intervention had made little difference to the parents in the study group, and had not necessarily been of real value to the study health visitors in identifying stresses.

Identification of Inter-personal Stresses

Inter-personal stresses involve those associated with close family relationships. As Watslavick (1967: 32) reminds us:

> Every part of a system is so related to its fellow parts that a change in one part will cause a change in all of them and in the total system. That is, a system behaves not as a simple composite of independent elements, but coherently as an inseparable whole (Watslavick,1967: 32).

Broderick & Smith (1979) have noted that adding and subtracting a single family member of a family has dramatic implications for its structure. The meanings that families attach to the death may both influence and be influenced by structural changes. Partners, other children and grandparents may all be affected and may affect each other. For this reason, the assessment tool included sections to enable the health visitors to identify any relationship difficulties with close family members. So did the assessment tool help study health visitors to identify difficulties within family relationships more

Table 2.8 Parents' Responses as to whether H.Vs had asked about relationships since the death		
Relationship after Death		
	Study	Control
with partner	12/23	14/26
with children	10/18	15/29
with grandparents	11/22	10/29

Again the findings show few differences between the groups, although more in the study group remember being asked about relationships with grandparents. Interestingly, the picture that the health visitors give on asking about relationships is slightly different and does not accord with the parents' responses.

Table 2.9 Health Visitors Responses as to whether they had asked about relationships since the death		
	Study	Control
With partners	46/50	35/43
With grandparents	40/47	31/43
With siblings	36/36	23/27

According to the health visitors, many more in both groups (and in particular the study group) asked about family relationships than the parents suggest, but this may have been due to difficulty in parents' recall; alternatively health visitors may have asked, but parents may not have noticed. It can be noted that slightly more study health visitors asked about relationships in all three categories which could be related to the assessment tool.

Identification of Extrapersonal Stresses

Extra-personal stresses may arise as a result of the attitudes from others outside the close family unit. Several researchers have shown that bereaved parents are frequently avoided by friends and associates (Brabant,1995; Worden, 1991; Thuen, 1997; Stroebe, 1993; Raphael, 1984), or well- meant attempts to support may be perceived by the bereaved as unhelpful (Lehman et al, 1986). The extent to which parents receive social support in bereavement is generally found to be related to the psychological adaptation process (Helmrath & Steinitz,1978; Jurk et al, 1981; Nicol et al, 1986; Tudehope et al, 1986; Thuen, 1997). Thuen (1997) has suggested that instrumental (practical) help from friends and neighbours can include a wide range of activities such as providing assistance with household chores, taking care of children, and providing transport. By reducing task loads and giving the parents an opportunity to focus their attention on the grieving process, he suggests that psychological adaptation may be helped.

In Phase 2, of those parents who responded, 15 of 23 (65%) in the study group and 13 of 30 (43%) in the control group reported that their health visitors had asked about relationships with friends and other family members since the death. Nearly a quarter more study parents had been asked, which could suggest that the assessment tool may have guided them.

Thus it can be seen, that on the whole, the bereavement assessment tool did not make a significant difference to the study group in asking about the intra, inter and extra-personal stresses. Having ascertained this, did the assessment tool encourage health visitors to continue visiting, in planning care and in supporting the bereaved families?

Continuing Visits by Health Visitors

Of the study parents, over four fifths reported that their health visitor had continued to visit after the first visit, in contrast to 23 of 32 (72%) health visitors in the control group. As the majority of study health visitors had continued to visit, it could be suggested that the intervention may have encouraged them to do so. The time between visits was considered satisfactory by slightly more of the study parents (6%). The number of visits from their health visitors was perceived as just right by 19 of 27 (70%) study parents and by 20 of 32 (63%) control parents.

However, it could be suggested that because all health visitors knew they were part of a study, they may have been encouraged to visit (Hawthorne effect, Roethlisberger and Dickson, 1964). The study health visitors knew they were part of a study as they had received the intervention prior to the commencement of the research. The control health visitors also knew of the study at three months from the death of a child, as they were sent questionnaires at this point. The questionnaires may have alerted them to the holistic principles of bereavement care, outlined in the bereavement assessment tool, giving them three months to put them into practice before the parents received their questionnaires at six months from the death. For this reason, an accurate evaluation of the intervention was less likely to succeed. In retrospect, it would have been more appropriate to have sent questionnaires to all health visitors at the same time as the parents, that is at six months after the death. Whilst in research terms, the method used, may have spoiled proper evaluation of the intervention, in human terms, it could be argued that the study design, although flawed, may have benefited bereaved parents. Instead of causing harm, the research may have been beneficial.

Involving Parents in Planning Care

As it has been suggested by several researchers (Hopson & Scally, 1977; Worden, 1983; Montgomery, 1993) that family members should be assisted to help themselves, the study health visitors were encouraged in the intervention to involve parents in planning care for their family. Over half the parents in both groups reported that they had been involved. While this is an encouraging finding, it was expected that this would have been higher in the study group than the control group as the study health visitors had been encouraged to do so.

Supporting Families

Partner Support

As over half the parents in each group reported that they had been asked about relationships with their partners, it could be assumed that in doing so the health visitors may have been able to help where there were difficulties. The parents were asked about the level of support they felt they had been given by their partner. In both groups this was high, 77% in the study group and 88% in the control group. The difference between the two groups is surprising. It could be suggested that the control parents may have had more stable relationships than the study parents, or that because the study group had more surviving children in their families than the control group, this may have caused an added strain on the parental relationship.

Support for Surviving Children

As was noted in the demographic information, more study parents had other children, 48 in the study group, compared with 34 in the control group. Nearly half of these children in each group were girls. Worden (1996) has suggested that in general, girls are more affected by the death of a sibling and boys more affected by the death of a parent. The reason for this is unclear but it could be suggested that this may arise from the facts that girls are socialised to relate to siblings in a more maternal way or that girls have learnt to show their feelings better than boys. In both groups, nearly all the bereaved children were over two years of age. Parents were asked if they had noticed any behavioural changes in their children since the death. Details of these changes are given in Table 2.10.

Table 2.10 Behavioural Changes in Siblings since death

	Study Group	Control Group
Becoming withdrawn	11/21	4/14
unable to concentrate	9/20	3/12
bedwetting	5/20	3/12
being bullied	4/20	1/12
bullying others	5/22	4/14
telling fibs	7/21	6/14
aggressive behaviour	12/22	12/15

Other behavioural disturbances noted by the parents included children being "clingy", needing more attention than before, showing off, and encountering sleep disturbances. Aggressive behaviour was the most commonly reported change in both groups of children, followed by telling fibs. The following table shows whether the health visitors provided information and/or guidance for the parents on helping their other children, and how useful this had been.

Table 2.11 Information & Guidance given to parents on helping siblings		
	Study Group	Control Group
provided information	14/19	10/19
found useful	8/14	6/10
gave guidance	14/19	13/23
found useful	10/14	8/13

Whilst three quarters of the study health visitors, compared to just over a half of control health visitors, provided information for the parents, the information the control health visitors did provide would seem to have been more useful than the information provided by the study health visitors However, in contrast, the question of giving advice suggested the opposite. Nearly a fifth more study health visitors gave guidance which was seen as more useful by parents as compared with that given by the control health visitors. This would suggest that the guidance given to the study health visitors in the booklet for health visitors, as part of the intervention, may have helped them in this part of their work. Table 2.12 shows what parents would have liked to help their other children.

Table 2.12 What parents would have liked to help siblings		
	Study	Control
more information	11/21	13 24
more guidance	11/18	12 20

From these results, more than half the parents in both groups would have appreciated more information and guidance on helping their other children. This would seem an area that requires further attention. Although the number of children referred to other professionals is small, it was slightly higher in the study group .

Table 2.13 Sibling Referral		
	Study	Control
psychologist	5	2
psychiatrist	1	3
social worker	0	1
ber. counsellor	6	1
Total	**12**	**7**

The reason for the greater number of referrals by study health visitors is unknown but it could be suggested that they were more aware of their own inability to help than the control group, and that the assessment tool and the booklet had alerted them more fully to bereaved children's needs. It may also be that study parents may have put more pressure on them for referral, which could also be linked to the parents' booklet.

Support for Grandparents

The parents reported that just over a half of the grandparents in the study group and around a quarter in the control group, had been included by the health visitors in their care. Whilst the numbers are very small, Table 2.14 indicates what grandparents were offered.

Table 2.14 Parents' responses as to what was offered to Grand-parents

	Study	Control
HV talked to them	¾	7/10
HV gave advice to parents to pass on	¾	2/9
HV gave them information	1/3	0
HV gave information to parents to pass on	1/3	1/9

Many grandparents may have lived some distance from the parents, and those who lived nearby, may have been the ones to whom the information was given. As mentioned previously in Chapter 4, there is a dearth of information on the support of grandparents. They tend to be the "forgotten grievers" (Ponzetti & Johnson, 1991), and yet they will have their own pain to deal with, whilst they assist their bereaved children Their grief is not often recognised, and their critical role in the adjustment of young parents who turn to them for support, may be ignored (Raphael 1984). It would seem beneficial, therefore, to identify and locate grieving grandparents, making available, suitable

leaflets as initial contact. Further research to develop models of support specifically for grandparents would seem to be warranted.

Support for Other Close Family Members

Just over a third of parents in the study group and a quarter in the control group reported that other members of their close family should have been given more support by members of the primary health care team. Whilst a health visitor's time is limited, checking out other members' needs and providing information may have been appropriate

Practical Difficulties

In relation to being asked about any practical difficulties, three quarters of study parents and just under two thirds of control parents reported that they had been asked. As more study health visitors had included this in their assessment, it could be suggested that the intervention may have assisted them in including this important factor.

Informational Support

What information were parents given by their health visitors on what to expect in bereavement and if so how helpful had this been?

Table 2.15 Bereavement Information given to parents by health visitors

	Study	Control
HV gave information	17/27	18/31
very helpful	8/17	11/18
fairly helpful	8/17	7/18
not helpful	1/17	0 (

Slightly more study health visitors were reported by the parents to have given information. Nearly all parents who responded had found the information very or fairly useful. In the study group, 21 parents had been given the booklet "What is Bereavement", which was included as part of the intervention; nearly half of these parents commented how useful it had been. It could, therefore, be suggested that the parents' booklet was a useful addition.

Although not statistically significant, slightly more study health visitors were reported by the parents to have offered support to other members of the family, considered practical implications and offered more information and guidance. However, the findings would suggest that the assessment tool did not make a significant difference to the study group of parents.

Parents' Perceptions of Support from Health Visitors

Although the assessment tool may not have helped greatly, how did the parents perceive the support from the health visitors? Table 2.16 gives the findings from the parents.

Table 2.16 Parents' Views of Health Visitors Support & Care

	Study (n=27)	Control (n=31)
very supportive	18	19
fairly supportive	7	7
not at all supportive	2	5
very caring	17	22
fairly caring	9	5
not at all caring	1	3

A high proportion of parents in both groups felt that their health visitor had been very or fairly caring and supportive which was very encouraging. More positive comments

came from the study group of parents. The study group is identified by "1" preceding the number, and the control group by "2" preceding the number. As one mother wrote:

> I have been very lucky this time. My health visitor has been a gift from the Gods. She has made herself available at any time. Previously I had a stillbirth and no-one came near me (10102).

Another mother wrote from the same group:

> If there is anything we want from our health visitor, we only have to phone her (10511).

However, it was clear that for some families in both groups, care could have been improved. The parents comments reflected this.

> My husband had little or no support; everyone seemed to bother about me and not him (10801).

> We have had to support our family without professional help in the best way we could. I do hope services can be improved in the future and that professionals accept that the death of a child is one of the most devastating experiences and that on-going help for as long as necessary would be extremely beneficial (22202).
> The past months have been difficult. I row with my partner and have run out of comforting words when she wakes crying. The only support we have had has been from friends and colleagues and our G.P has seen my wife on several occasions (22218).

> I feel a little neglected by professionals as their support has dwindled over the last few months. I suppose people think we are recovering, or that they may be intruding and I will ask for help if needed (21302).

> The only person that has helped us is the consultant, otherwise we were left on our own. It makes you think you did something wrong because we had no help, even though we had nothing to do with our baby's death (10308)

These comments suggest that support needs to continue for as long as families want it.

So at six months from the death were health visitors still visiting the bereaved families?

Table 2.17 Parents comments on visiting by their health visitors		
	Study (n=25)	Control (n=31)
yes & I find it useful	11	10
yes, but not useful	0	2
no, but I would welcome it	7	5
no, but I wouldn't want her to	2	3
no, but I don't need HV now	5	11

As Table 2.17 shows, again there were few differences between the two groups of parents. A minority of parents would have liked their health visitor to continue but it was encouraging to find that a fifth in the study group and over a third in the control group no longer required help.

In asking the parents if they felt they could contact their health visitor if needed, 27 of 34 (79%) in the study group and 26 of 38 parents (68%) in the control group replied that they could do so. One mother from the study group replied:

> So much bad is said about the health service that I wanted to write to say how good our care has been (10806).

Support from Family and Friends

Whilst it was clear that for the majority of parents care and support from their health visitors had been satisfactory on the whole, how did the bereaved parents rate the support from family and friends? Table 2.18 gives their responses.

Table 2.18 Support for Bereaved Parents			
From:	Study	Control	Overall
Family	28/30 (93%)	34/37 (92%)	62/67 (93%)
Friends	25/31 (81%)	33/37 (89%)	58/68 (85%)

The support received from friends and family is perceived by recently bereaved parents as remarkably high in both groups, in comparison to that received by parents in Phase 1,

where only just over a quarter of parents felt supported by friends. As most health visitors in both groups had continued to visit, this could account for the change, as health visitors may have encouraged friends to be involved. Certainly there was evidence from one parent in the study group that her health visitor had spent some time with her friends and neighbours in discussing aspects of grief and how best they could help. Alternatively, because there would seem to have been more media coverage on bereavement in recent years and an increasing selection of books on the subject, people generally may be more aware of the need to support the bereaved. This finding was very encouraging.

As support from the families' health visitors and their friends and family would seem to have been satisfactory, how did parents view their support overall?

Table 2.19 Parents' Satisfaction of Support overall

	Study (n=32)	Control (n 37)
very satisfactory	11	20
fairly satisfactory	20	14
not at all satisfactory	1	3

Of the study group of parents, 97% had considered their overall support as very or fairly satisfactory which was slightly higher (5%) than the control group, although over half in the control group reported that it had been very satisfactory. In contrast to Phase 1, it would appear that support from both informal and formal sources has improved.

So whilst support was considered good on the whole, did the parents make more visits to their G.P than normal?

Parents'Visits to G.Ps after the Death

The research asked parents about visits to their G.Ps over the six month period since the death of their child As we have seen bereavement is an holistic experience affecting the physical, psychological and social aspects of their lives. Parents may go to their G.Ps with clear psychological problems or with physical symptoms which may reflect difficulties in coping with current life stresses (Wienman & Goulston, 1991). Table 2.20 shows the number of visits parents made to their G.P after their child's death.

Table 2.20 Parents' Visits to G.P after the death

	Study (n 34)	Control (n 37)
not at all	6	4
once	2	7
2-3 times	10	15
4-6 times	7	3
more than 6 times	9	8

Most parents in both groups visited 2-3 times over the six month period since the death, and around a quarter of all parents had visited more than six times. The reasons for parents visiting their G.Ps is not known. However, only six months after their child's death, it could be expected that parents would feel depressed and possibly anxious which could be manifested in physical ailments or mental health problems. Wienman & Goulston (1991) suggest that most non-bereaved people seek their G.P's help on only a few occasions each year, so the presented data on bereaved parents shows a slight increase in the number of visits to their G.Ps. The fact that the parents had received good support from their health visitors may have obviated the need for more frequent visits to their G.Ps. Nonetheless, there was evidence that the mothers especially were quite anxious and depressed at six months after the death.

Anxiety and Depression of Parents

It could be expected that bereaved parents may feel anxious and depressed in the months following their child's death. To determine whether there were any differences between the parents whose health visitors had used the assessment tool and may have received better support, and those who had not, thus reducing anxiety and depression levels, the Fould's Bedford Anxiety and Depression Scales (1978) were used.

Worden (1983) has suggested that anxiety comes primarily from two sources. Firstly survivors feel that they will be unable to survive without their child. Secondly anxiety relates to a heightened sense of personal death awareness- the awareness of one's own mortality increased by the death of a significant loved one. In assessing the emotional stresses on the parents in Phase 2, they were asked to say how anxious and depressed they felt in the week before completing the questionnaire. This was around six months from the death.

The Foulds-Bedford Anxiety and Depression Scales (1978) were used primarily to determine any differences between the groups that the intervention may have made, but were also useful in identifying any differences between fathers and mothers. In this case, data were taken from all who completed questionnaires. Tables 2.21 and 2.22 show the number of points of anxiety and depression of the parents.

Table 2.21 Points of Anxiety in Fathers & Mothers				
Points	Study Group		Control Group	
	Fathers (n=19)	Mothers (n=32)	Fathers (n–25)	Mothers (n=35)
0	6	5	8	6
1	2	3	5	4
2	0	4	6	5
3	3	3	0	5
4	1	4	3	6
5	3	4	1	4
6	3	5	2	2
7	1	4	0	3

In each group, nearly a third of fathers reported no feelings of anxiety and the number of mothers is almost comparable. There were eight fathers in the study group expressing four or more points of anxiety, and six in the control group, whilst over half the mothers in the study group and somewhat less in the control group reported high levels of anxiety. Thus more mothers than fathers expressed greater anxiety and more of the mothers in the study group were more anxious than control mothers.

Depression in Parents

Table 2.22 Points of Depression in Fathers and Mothers				
	Study Group		Control Group	
Points	Fathers (n=19)	Mothers (n=32)	Fathers (n=19)	Mothers (n=35)
0	6	5	8	5
1	3	6	4	6
2	1	0	3	8
3	2	6	4	8
4	2	5	4	4
5	3	4	1	0
6	2	3	0	2
7	0	4	1	2

Nearly a third of fathers in both groups reported no feelings of depression; while fewer mothers reported no points of depression, the number was almost the same in each group. Of those parents expressing four or more points of depression, there were almost a fifth of study fathers and a quarter of control fathers; of the mothers, there were half in

the study group and a quarter in the control group. Although the numbers are small, it can be seen that fathers reported less feelings of depression than mothers. This accords with other studies (Vance, 1991, Riches, 1996).

Whilst these findings confirm the findings from other studies, there is no definite evidence to show that the assessment tool made any significant difference to levels of anxiety and depression of the parents in the study group

Some of the comments made by parents show their pain and anguish:

> The pain will never go away. We love our son so very much. He was so bright. He used to help me with my spelling as it's so bad (21406)

> More people wanted to talk to my partner than me (health visitors, doctors). To start with, I couldn't be bothered to speak to anybody, nor to this day. I don't really know how to express myself unless I am asked questions. This is probably the most I've ever said to anyone (in this questionnaire). I am always embarrassed that I will cry which makes me angry. This makes me feel very low. It's as if I locked away the feelings in hospital when my son died, but the feelings have a real good pick at the locks sometimes (10402).

One mother wrote on her partner's behalf:

> My partner visited his G.P to ask for the help of a psychologist, but he was given a bottle of pills which just zonked him right out. My partner is very depressed at the moment and I feel it has all been left to me to handle (21405).

However, for both fathers and mothers in the study group, more reported depression than the control group. While the study mothers and fathers would seem to be more depressed, the results are statistically not significant. The fact that study families had more children (18% more) may have accounted for higher levels of anxiety and depression in the study mothers. Not only did mothers have their own grief to deal with

but also those of their children who may have been reacting to the death. Other factors, not known to the study, may also have contributed to higher levels of anxiety and depression in both groups. These include unresolved past losses, past or present poor mental or physical health, personality, the manner in which the death had been dealt with in hospital, and even the way in which the funeral had been conducted. Financial difficulties and relationship difficulties may also have added to increased anxiety and depression.

It could be argued that *where the assessment tool was used, parents may benefit in the* longer term by having less depression and anxiety for less time as a result of the support given by health visitors. However, without further research, this cannot be proved. Lehman's study (1987) on the long term effects of losing a spouse or child in a motor vehicle crash, suggested that even after four to seven years after the death, it continued to occupy their thoughts and cause distress. However, it is not known whether the families in his study had received good support or not.

In the concluding part of this chapter, the parents' views as to which professionals they considered appropriate to support bereaved families, are presented.

Appropriate Professionals to support Bereaved Families

In Phase 1 it was established that parents would have liked more support from members of their primary care team. This would appear to have been achieved in Phase 2, especially by health visitors. Nonetheless, parents reported that they felt G.Ps were the

most appropriate professionals to support them, although health visitors came a close second as shown in Table 2.23

Table 2.23 Parents' opinions as to appropriate professionals to support bereaved families

	Study	Control
G.P	29/31	33/35
Health visitor	23/29	28/31
social worker	4/24	5/24
bereavement counsellor	20/28	23/30
member of the clergy	12/29	16/26
hospital doctor	16/28	10/28
hospital nurse	4/24	7/24

After G.Ps and health visitors, bereavement counsellors were rated quite highly. Hospital nurses and social workers in both groups were rated the least appropriate.

Summary

From the information given by the parents, there were few differences between the two groups in terms of gender, age and cause of death of their children who had died. There were also few differences in age, status, employment, health and ethnicity which could have biased the intervention. Study parents had more surviving children and control parents generally had more time off from work as a result of the death. The level of contact that families had with their health visitors before the death was comparable and most health visitors in each group made contact with the families soon after the death. The parents in both groups reported that it was easier to talk to someone they already knew about their child's death

It was disappointing that the bereavement assessment tool did not make a more significant difference to parents being asked about the various dimensions of grief. It could, therefore, be suggested that more training is required on the holistic, psycho-

social model adopted if it is to be useful. It could also be suggested that for health visitors to adapt to a model other than the medical one, may take some time.

However, this study has shown that both groups of parents rated the care and support of their health visitors quite highly. Combined with good support from friends and family, the majority of parents perceived their overall care as satisfactory. This is in direct contrast to Phase 1 where the majority of parents felt isolated and unsupported. The fact that all the health visitors in the study knew they were part of research may have been the reason that they continued to visit after the death.

Because most parents in both groups in Phase 2 had a high degree of support from their families and friends, it may have reduced the need for more health visitor input. It could be suggested that where there is good informal support, the involvement of a health visitor is less necessary. Conversely, the health visitors in both groups may have been instrumental in facilitating better provision of support and resources from friends, partners and families. At six months after the death, a fifth of study parents and just over a third of control parents felt they no longer had need of their health visitors' support.

The number of parents' visits to G.Ps was not appreciably different in the two groups and was almost comparable with the number of visits made by non-bereaved people. The majority of parents in both groups rated their G.P as the most appropriate professional to support them but health visitors were also rated highly.

The levels of anxiety and depression were slightly higher in the study group of parents but not significantly different. Mothers were found to be more anxious and depressed than fathers which accords with other studies.

From the parents' view point, this study has shown that whilst the assessment tool may have assisted the study health visitors in their care and support of families, it did not make a significant difference. However, support and care given by both the study and control health visitors was considered satisfactory by the majority of parents.

Having considered the parents' responses, were there any differences between the two groups of health visitors and how was the intervention rated by the study health visitors? The next chapter will discuss these questions.

CHAPTER 10

HEALTH VISITORS' ASSESSMENT OF THE INTERVENTION

Introduction

The last chapter showed that the intervention for the study group of parents did not make a significant difference to their support, although slightly more study parents had been asked by their health visitors about intra and extra personal aspects particularly. This chapter will firstly consider the background of the study and control health visitors to determine any difference that might have biased the evaluation of the assessment tool. Secondly, the study health visitors' evaluation of the intervention will be discussed. Lastly, the training wanted by health visitors and the support they require will be examined.

Response from Health Visitors

As in Phase 1, the response of health visitors in both groups was high. Of 85 study health visitors, 64 (75%) responded. In the control group of 78 health visitors, 17 were excluded as their managers did not want them included because of likely increased work overload. From a possible 61 control health visitors, 46 (79%) responded. As 5 of the study health visitors had not received the pack, and therefore were not aware of its contents, questionnaires returned from them were changed to controls, making a total of 59 study and 51 control health visitors.

The Background of the Health Visitors

In order to establish if there were any differences in background between the two groups of health visitors, which might affect the assessment of the intervention, they were asked about the length of time they had practised as health visitors, their experience of child death, any training they had received in this area of care, whether policies to guide them were available in their health districts, and how well they had been supported when caring for their currently bereaved family.

The findings showed that in terms of work experience, the two groups were very similar. The median number of years practising as a qualified nurse and health visitor are shown in Table 3.1.

Table 3.1 Health Visitors Previous Work Experience

	Median number of years	
	Study (n=59)	Control (n=51)
practised as a HV	10 (from 1-37 years.)	11 (from 1-33 years)
practised as a trained nurse	7 (1-23 years)	8 (from 1-23 years)

With regard to their experience of child death, again the responses showed little difference, as can be seen in Table 3.2.

Table 3.2 Experience of Child Death

	Study (n=59)	Control (n=51)
the present death being the first time	12	13
twice	18	15
three times	15	12
four times or more	14	11

For around a quarter in each group of health visitors, this was their first experience of caring for a bereaved family after sudden child death. The number of health visitors in each group who had experienced two or more child deaths was also comparable. In breaking down the health visitors' experience of any type of child death, it can be noted

in Table 3.3 that the differences are minimal, although fewer study health visitors had experience of cot death, and cot death was the commonest type of death met in both groups.

Table 3.3 Deaths experienced by Health visitors

Cause of Death	Study	Control
cot death	85	80
infection	28	18
accident	16	9
life- threatening disease	23	16
Non accidental injury	2	0
termination of pregnancy	2	0
stillbirth	0	3
Total number of deaths	**156**	**126**

Training

In Phase 1 it was established that three quarters of health visitors had received no bereavement training, and so the majority felt unable to support families whose children had died. In Phase 2 the results were very different as is shown in Table 3.4.

Table 3.4 Bereavement Training given to Health Visitors

	Study	Control
General Bereavement	40 59	32 51
Meeting needs	30 40	27 32
Specific to child death	19 59	17 51
Meeting needs	18 19	14 17

Nearly two thirds in each group had received training on general bereavement and a third specific to child death. The majority of health visitors stated that such training had met their needs. Thus it could be argued that it may have been bereavement training that had made the difference to the support of bereaved families in Phase 2, in which case the intervention may have made little difference. One of the recommendations in Phase 1 was to improve health visitors' training so that they would feel better equipped to deal with bereaved families. This would appear to have been taken up.

The fact that the Confidential Enquiry into Sudden Deaths in Infancy (CESDI) was being conducted in the South & West region during the first year of Phase 2, may have also contributed to health visitors' better understanding of families' bereavement. As part of that study, after each infant death, a case conference was held with those involved, which gave an opportunity for professionals to look at their care. Thus, it could be suggested that both the CESDI study and the training of health visitors had made a difference to the better support of bereaved families in the South & West region.

It was found that many of the health visitors had known the families before the death, which may have contributed to their need to offer follow-up. Table 3.5. gives details of previous contact.

Table 3.5 Previous contact with bereaved Family

	Study (n=59)	Control (n=51)
many times	33	30
a few times	19	15
once	4	5
not at all	3	1

Over half in both groups of health visitors had visited the families on many occasions, only a small number not knowing the families before the death. So did previous contact make it easier to visit after the death?

Table 3.6 Previous Contact making it easier to visit after the death

	Study (n=50)	Control (n= 48)
helped a lot	38	41
helped a little	10	4
didn't help	2	3
made no difference	0	0

The majority of health visitors in each group reported that it had helped greatly to have had previous contact with families before the death although more control health visitors

than those in the study group reported that this was the case. However, even with previous contact, there may have been differences between those who had received the intervention and those who had not. Were there policies in health districts to guide and advise the health visitors on caring for bereaved families?

Policies for caring for a Family after sudden Child Death

Whilst there would appear to be few differences in experience, training and previous contact with families before the death between the groups of health visitors, the main identifiable difference in Phase 2, lay in the provision of policies within health districts to guide health visitors when caring for a family where a child had died. Of 59 study health visitors, just over a half knew of a policy which had guided the majority in supporting their bereaved families. In the control group, of 51 health visitors, only five (10%) knew of a policy which had helped three of them.

Thus more health visitors in the study group were aware of and helped by district policies which could have made a difference in care, although as was seen in the last chapter, the parents' views of their support from health visitors was very similar in both groups. Thus policies to guide health visitors would seem to have made little difference to the families' support. However, as one study health visitor commented:

> Each health district should have a clear policy on bereavement care of families (10512).

It could be suggested that existing policies may require scrutiny and/or updating by health authorities to ensure that relevant and helpful guidance is given to health visitors when supporting bereaved families. In addition, any policies developed, should be made

known to health professionals, so that easy access may be procured. With few policies available to help and guide health visitors, many may have felt anxious and lacking in confidence before visiting.

Many in Phase 2 expressed how difficult it was to make the first visit, especially when they had known the deceased child:

> I felt I had nothing to offer the family. Would I be a painful reminder of a well and alive baby? (22103).

Some health visitors, dealing with their own personal bereavements, and others who had their own children, were worried as to how they would react to the bereaved families. For those with no experience and no training, they were worried about using the right words, their adequacy in offering support, and the parents' reactions. Others were anxious about intruding on the family's grief.

> I was unsure of the family's grief reaction. Would I be able to help the family? (10401).

Levels of Anxiety and Confidence before Visiting

For this reason, the health visitors were asked to state how anxious, confident and comfortable they felt before and after the first visit This was measured on a scale of 1-10, (1-3 = very anxious, uncomfortable and not confident, 4-7= moderately anxious, uncomfortable and moderately confident, 8-10 not at all anxious, very comfortable and very confident). Table 3.7 shows the results before and after the first visit.

Table 3.7 Levels of Anxiety, Comfort and Confidence of Health Visitors				
	Before first visit		After first visit	
	Study (n 59)	Control (n–51)	Study (n 55)	Control (n=50)
very anxious	24	20	9	5
mod. anxious	25	24	21	15
not at all anxious	10	7	25	30
very uncomfortable	20	12	9	5
mod. comfortable	29	28	20	13
very comfortable	10	11	26	32
not at all confident	14	12	7	7
mod. confident	29	26	30	23
very confident	16	13	18	20

There would appear to be few differences between the groups before visiting, although it was noted that around 40% in each group felt anxious before visiting, and 10% more in the study group felt uncomfortable. After the first visit, levels of anxiety reduced considerably in both groups. It could be argued that the study health visitors were more aware of the issues around bereavement because they had received the information pack and therefore were more anxious, less comfortable and less confident because they were dealing with a psycho-social model rather than a medical one. The responses from the study health visitors on whether the assessment tool, in particular, had reduced anxiety in planning care are shown in the following Table.

Table 3.8 Study Health Visitors Anxiety about using Assessment Tool		
	when planning care (n=35	subsequently (n=32)
Increased anxiety	5	2
didn't make any difference	17	23
reduced anxiety	13	7

For the minority, the assessment tool had increased their anxiety but for over a third it had reduced their anxiety. For the majority it had made little difference. However, nearly two thirds reported that the assessment tool gave them a better understanding of

bereavement care, a third felt that it gave them more confidence and nearly half reported that it had encouraged them to visit. So did the assessment tool make any difference to the study health visitors' visiting pattern?

Health Visitors' Contact with families over a three month period

Table 3.9 shows the health visitors' contact with the families over the first three months after the death.

Table 3.9 Health Visitors' Contact Time with Bereaved Families over 3 months since the death

	Study (No of HVs=59)				Control (No HVs=51)			
	No	Average	Time	Average	No	Average	Time	Average
home visits	220	3.7	232 hours	3.9 hours	176	3.5	180 hours	3.5 hours
phone calls	97	1.6	18 hours	0.3 hours	86	1.7	17 hours	0.3 hours
Seen in Surgery	22	0.4	13 hours	0.2 hours	22	0.4	13 hours	0.3 hours
Total Contacts	**339**	**5.7**	**263**	**4.4**	**284**	**5.5**	**210**	**4.1**

The number of home visits are very slightly higher in the study group, although the results are very similar in both groups. The average number of total contacts from both control and study health visitors is around five per family over a three month period. The time spent with each family amounts to on average four hours in both groups, although this is slightly higher in the study group. Over half in each group were still visiting the families after three months.

Table 3.10 Continuing Visits by Health Visitors

	Study (n=58)	Control(n=51)
still visiting	35	27
Not visiting	23	24

Although the number of visits and hours spent with bereaved families is similar, a slightly higher proportion of study health visitors were continuing to visit after three

months. Nearly half (18/40) the study health visitors who had used the assessment tool, reported that it had encouraged them to continue visiting which could account for the difference.

Whilst caring for the bereaved families, was there any difference in support for the health visitors in each group?

Support for Health Visitors

As was seen in the last chapter, the majority of bereaved parents felt they had received adequate support. For health visitors supporting a bereaved family, there can also be various stresses. Immediate support on a practical level may include co-ordinating services, explaining procedures, liaising with the G.P. and providing medical information. Although health visitors are trained to give advice and help, in the case of a child death, they are also required to be active listeners, allowing the family to talk through their feelings. As Hindmarch (1993) suggests listening is a complex activity which includes giving attention, receiving information, taking in the thoughts and feelings conveyed, interpreting behaviour, noticing key points and themes and checking that they have understood correctly.

Health visitors may also have had to deal with their own personal issues around death or loss, evoked by the present death. Their own children or grandchildren may have been of similar age to the deceased, and therefore health visitors may have become more aware of the fragility of their lives. When health visitors have known a family and the

deceased child before death, it is likely that they may have their own feelings of sadness and perhaps even guilt at the death of the child, especially after a cot death. Such a death may raise questions of guilt for them over whether they had missed some important clinical feature when the baby was still alive, which may have caused the death.

Comments from the health visitors demonstrate how they felt.

> The sudden death of a child is a highly stressful event for all involved, including the families' health visitors (2103).

> In the face of such a loss to the family, I felt I had little comfort to offer. I have children of my own and felt their vulnerability more intensely. "There but for the grace of God go I" (10301).

> I was trying to do the right thing for the family which is not necessarily what I considered to be appropriate to my own thoughts and feelings (21703).

For all the above reasons, support for health visitors would seem essential, so did the health visitors in the study receive support and was there any difference between the two groups? Table 3.11 shows their replies.

Table 3.11 Available Support for Health Visitors

	Study	Control
Colleagues	46 51	42 47
their own family	17/52	12 45
the bereaved family	4/51	6 44
friends	7 51	5 43
the Church	8 51	2 43
support group at work	0	6 44
counsellor at work	1/50	1 43
private counsellor	0	0
other	10/50	9/44
no-one	28/50	30/45

The greatest number in both groups relied on colleagues for their support, and yet over half in the study group and two thirds in the control group reported that they felt they

had no-one to support them, which would seem a contradiction. The Church, in whatever form, had helped more in the study group, and 6 control health visitors had access to a support group within their district where the study health visitors had none. It would appear, therefore that there were few differences in levels of support. Was the support that was offered considered adequate?

Table 3.12 Adequacy of Support for Health Visitors

	Study (n 58)	Control (n=51
adequate support	29	21
inadequate support	12	17
not sure	17	13

The adequacy of support was higher in the study group, but was nonetheless low in both groups, a fifth in the study group and a third in the control group reporting that their support had been inadequate. Interestingly, the results on support of *health visitors in* Phase 1 showed, as in Phase 2, that colleagues offered the most, but over half said they had also received support from management, 29% had access to counselling and 8% attended a support group. However, in Phase 1, as these were not necessarily the health visitors of the deceased children, no direct comparisons can be made. Support for the health visitors in Phase 2 who had experienced a child death and were supporting these families would appear to be inadequate for the majority in both groups.

The majority of health visitors in both groups in Phase 2 expressed the need for better supervision from someone trained in bereavement care who could support, advise and encourage them.

> I would have liked debriefing, closer monitoring of visiting pattern and encouragement in clinical supervision from someone knowledgeable and trained (21908).

> I feel very strongly that health visitors should have access to a trained confidential, counsellor, so that when health visitors feel they need extra support, they have ready access to them (10202).
>
> Although I feel that I am able to support this family, I feel quite isolated in having to carry the "baggage" that comes with it. Supervision or someone with whom to off-load, would have been very useful (21908).
>
> With hindsight, I think a regular more structured chance to discuss progress would have been useful (20402).
>
> I would have appreciated a named counsellor in the authority to go to, to be reassured that I did it right! (21301).

Many health visitors would also have valued a referral point for information and resources, for the need to have an experienced resource person for reference, for gauging their input to families and for better formal support for themselves. One of the suggestions for empowering health visitors in Chapter 8 was to provide a resource for them. This idea was rejected because of possible financial limitations. However, this study has shown that health visitors would value this. The fact that more health visitors are being given bereavement training would suggest that they are being viewed as appropriate professionals to take on a supportive role of families and for this reason, may need more support and resources. Thus health authorities may, in time, have to consider appointing resource health visitors. The cost of doing so may not be so great as was first envisaged. By identifying an interested health visitor, already in employment within a health authority, by ensuring that she was given sufficient training, a resource could be set up for other health visitors. In Phase 1, the mean number of deaths per annum in one health authority was 9 (ranging from 3-17), although this was slightly lower in Phase 2. Thus the demands on a resource health visitor are not likely to be

great, and any post set up could be part-time or as part of other duties and responsibilities.

If we are to value health visitors' role in supporting bereaved families, then it would seem appropriate to offer suitable resources to support them in their valuable and difficult role. Hindmarch (1993) suggests that the function of supervision is for support, clarification, co-ordination, evaluation, advice/consultation and protection. As Tschudin (1987) suggests:

> The fact that we deal with people who are vulnerable makes us vulnerable too, and if we are to remain truly human when coping with our own difficulties and those of other people, then we need to be supported, for our own good and the good of those for whom we care (Tschudin, 1987:128).

Other professional groups such as social workers and psychologists have supervision built into their job descriptions (Tschudin, 1987), so it would seem reasonable to suggest that health visitors are also provided with supervision, especially as they are dealing with one of the most difficult and sensitive areas of life- that of supporting families after child death.

As both groups of health visitors considered their support inadequate, were there any differences between the groups in terms of how effective the health visitors believed their care had been? Again, using a scale of 1-10 (1-3 very ineffective, 1-7 moderately effective, and 8-10 very effective), Table 3.13 shows how health visitors rated their care to the bereaved families.

Table 3.13 Health Visitors Perceptions of Effectiveness of their Care		
	Study (n 56)	Control (n=47)
ineffective	11	10
mod. effective	32	27
very effective	13	10

There would appear to be few differences between the groups, the majority considering the effectiveness of their care as moderately or very effective. Although parents were not asked how effective they felt the health visitors' care had been, these results link with the parents' perceptions where most health visitors were considered caring and supportive. The majority of all health visitors felt that they had been effective in helping the family to function together, and in using appropriate resources.

Table 3.14 Effectiveness of Interventions		
	Study	Control
to function as a family	20/29	17 22
utilising appropriate resources	35/42	28 34

So whilst there were few differences between the groups, how useful did the study health visitors consider the assessment tool and the booklet for health visitors? Table 3.15 looks at the usefulness of the assessment tool.

Table 3.15 Study Health Visitors' Views on the Usefulness of Assessment Tool (n=59)	
Not helpful	3
mod. helpful	24
very helpful	32

The majority had found it moderately or very helpful, and in commenting on its length, of those who replied (n=35), most (71%) had found it just right. So whilst it was found useful, did the assessment tool help in better planning of care for bereaved families?

Table 3.16 Using the Assessment Tool to plan Care (n=35)	
Helped in planning care	21
Didn't help in planning care	4
Made no difference	10

As can be seen from this Table, only 35 of 59 (59%) study health visitors had used the assessment tool for planning care. It was disappointing that nearly 40% did not use it. The reasons the health visitors gave for not using it were that it was inappropriate to use with some families because it was too long, or that other parents wanted to talk freely. Whilst it was not intended that all the sections should be attempted at one visit, this may not have been made sufficiently clear to the health visitors. However, it could be suggested that even if they had not used the assessment tool directly with the parents, the concepts may have been picked up as slightly more study parents reported that they had been asked by their health visitors about intra and extra personal stresses particularly. Of those who had used it, the majority had found it useful. Even if they hadn't used it, most (80%) of the study health visitors believed that all health visitors should have access to the assessment tool which could suggest that despite increased training, they require more guidance.

The Health Visitors' Booklet

The intention of providing the booklet for study health visitors was to make information easily available on caring for bereaved families, and to guide them in using the assessment tool. Of the 36 health visitors who responded, 28 (78%) considered that the information booklet for health visitors, "Guidelines for Health Visitors" had assisted them in using the assessment tool, two health visitors said that it had not, and six (16%)

said it made no difference. Nearly all (94%) felt that all health visitors should have access to the booklet.

Appropriate Professionals to Support Bereaved Families

Phase 1 demonstrated that bereaved parents, health visitors and G.Ps considered that health visitors were appropriate professionals to take on a supportive role, and the parents in Phase 2 reinforced this. The results in Phase 2 showed that 53 of 59 (90%) study health visitors and 47 of 51 (92%) control health visitors believed that they had an important role in supporting bereaved families after the sudden death of a child. The majority of health visitors also stated that because they knew the family before the death, they were in a good position to make further visits, could offer practical and emotional help and would know local resources. However, from the many comments made by the health visitors in Phase 2, it was clear that whether they had a key role, would depend on family needs and whom the parents chose.

> An individual family should decide whom they trust and feel most comfortable with (10909)

Possibly for this reason, the majority of the health visitors (91%) rated general practitioners highly as appropriate professionals to offer support to bereaved families. Over two thirds felt that bereavement counsellors (if available) were also suitable. Social workers and hospital doctors were considered the least appropriate by only 6% overall, the clergy by nearly a half, and hospital nurses by nearly a fifth. The results from the parents show similar findings, although hospital doctors were regarded more highly, possibly because of information needed about the medical issues surrounding the

death. Whilst my initial belief was that policies should be available to health visitors, I now see that a well constructed and known policy on caring for a family after the death of a child, should be available to any professional involved with a bereaved family.

Further Training wanted by Health visitors

Whilst training in whatever form would appear to have increased, there are still areas that health visitors would like covered as is shown in Table 3.17.

Table 3.17. Training wanted by Health Visitors on Child Death

	Training		Information	
	Study (n=59)	Control (n 51)	Study (n 59)	Control (n 51)
special needs of parents	36	35	15	13
helping siblings	38	35	16	15
planning care	26	34	18	14
available resources	19	20	25	29
support for HVs	21	23	17	13

It can be noted that more control health visitors want training on all the above areas in comparison to the study group. Just over two thirds, nearly a fifth more than the study group, wanted guidance on planning care. This difference could be attributed to the fact that the study health visitors had received the information packs which gave such guidance. The results also showed that health visitors in both groups would value training on the special needs of parents and helping siblings particularly. Bereaved parents with other children, both in Phase 1 and 2, wanted more information and guidance on helping siblings so this would seem to be an area that requires inclusion in training courses.

Health visiting is a preventive service offering advice and support to families, especially to mothers of young children (Taylor and Field, 1993). For this reason, it would seem

appropriate that health visitors are given some guidance on the grief of children and how best to help their parents cope with this. Also, bereaved parents in Phase 2 were seeking more information and guidance on helping their bereaved children. Harrington (1999) has suggested that various methods exist for helping bereaved children, ranging from simple, practical advice from primary care professionals to lengthy treatment programmes and yet both Phase 1 and 2 showed that this was not the case.

In Worden's Harvard Child Bereavement Study (1996) 125 children were followed for two years after the death of a parent, using a matched control group and non-bereaved children. He found that bereaved children were at greater risk of emotional and behavioural difficulties and that the effect was greater at two years after the death (21% compared to 6%). The study demonstrated that low esteem, anxiety about relationships can result from childhood bereavement. Whilst his study was concerned with parental loss, Worden (1996) suggests that overall, the death of a sibling does not portend more emotional/behavioural problems that the death of a parent. However, Worden's research (1996) showed that not all bereaved children needed or would necessarily benefit from counselling, the majority of children doing well without special intervention. Whilst the bereaved children showed a variety of changed behaviours, similar to those found in Phase 1 and 2, many of the so-called "disturbed" reactions were short-lived and ceased in time without intervention. For most children, grief is a normal reaction to loss and specialist or "expert" help is not required by the majority. Like bereaved adults, bereaved children need to be understood, to be heard, and to be valued for their unique feelings by those who play a significant part in their lives. This would suggest, therefore,

that health visitors in caring for a family where a child dies, need guidance on the grief of children, so that they can help the parents to help their children.

Children's lives, child health care and responses to children's grief have undergone major changes over the last 150 years (Lindsey, 1996) Lindsey suggests that we may now be entering a crucial period for the re-construction of our ideas of "childhood" and that our approaches to children's loss and grief will, as a result, undergo a major shift in focus. This shift, I believe has already started.

Currently, there is an increasing interest in bereaved children. In a recent publication of "Lifeline" (Summer, 1999), the journal of the National Association of Bereavement Services (NABS), pages 9-37 were devoted specifically to child bereavement. Reports were given of many recently founded services offering help to grieving children. The newly formed Childhood Bereavement Project, funded by the Diana Memorial Fund, has recently been set up to further the needs of grieving children. The overall aim of the project will be achieved through: the development, promotion and co-ordination of a national strategy and network of services for bereaved children, the establishment of a nation-wide forum for debate and action, the establishment and promotion of national standards and codes of good practice for working with the client group, co-ordinating and promoting training opportunities, co-ordinating and providing an information exchange and educational resource for anyone working with the client group, their families, health professionals and educationalists, the media and general public, co-ordinating, promoting and supporting educational policies and initiatives to reflect issues of loss and bereavement; finally, co-ordinating, promoting and generating

research into the needs of the client group. Regional groups have now been convened in the 14 regions of the U.K. where much interest has been showing in continuing such groups. Many of those who have attended, have come from the voluntary sector, from adult and children's hospices and from bereavement agencies dealing with bereaved children. The main part of their professional work is in dealing with dying, death and bereavement.

Whilst it would seem an ideal opportunity for the statutory and voluntary sectors to join together in these meetings, only a small part of the health visitor's role is in dealing with bereaved families. So such meetings may not meet their needs, especially as they require support and help at the time of caring for a bereaved family rather than when there is a meeting. It could further be suggested that health authorities should take some responsibility for support of their own professional workers, rather than relying on the voluntary sector. As was demonstrated in the last chapter, a fifth of health visitors in the study group and a third in the control group reported that their support had been inadequate.

The Child Bereavement Project, recently formed, may help in educating the general public about children's grief, but this will take time. Although regional meetings have been set up by the Project to help professionals dealing with bereaved children, they may not be appropriate for health visitors who need local help when they have a bereaved family on their case loads. Many health visitors reported that they would value more and better local supervision and an available resource within their health authority for whom to turn for advice, guidance and encouragement.

Summary

The information from the health visitors revealed that there were few differences in the their backgrounds in terms of length practising as health visitors, experience of child death, in knowing the bereaved families beforehand, and in support for themselves, which could have influenced the evaluation of the intervention. In Phase 1, it was found that only a quarter of health visitors had received any form of bereavement training. In contrast, the majority of health visitors in each group in Phase 2 had attended bereavement courses, the majority reporting that such training, had met their needs. This was an encouraging finding and could be the reason why the results from the parents were so similar. If this is the case, it highlights the importance of bereavement training. Health visitors in Phase 2 may also have been helped by the CESDI study.

However, two thirds of the health visitors in Phase 2 wanted training on helping bereaved siblings. Although the majority of bereaved children may show reactions to the death of either a parent or a sibling, most children will not require specialist intervention. However, their parents need to know that most behavioural changes are normal and will cease in time. Health visitors, therefore need information or training on the grief of children and how to help parents deal with bereaved children.

In terms of anxiety and lack of confidence before and after the first visit, there were few differences between the two groups of health visitors; in continuing to visit and visiting patterns, although the findings from the study health visitors showed marginally higher

figures. It was encouraging also to find that the majority of health visitors in both groups, were still visiting the bereaved families at three months from the death, most health visitors in both groups considering their care as moderately or very effective.

Nonetheless, it was revealed that support for health visitors would seem inadequate and that proper supervision in line with other professionals is considered a priority.

Whilst the intervention would appear to have made little difference to the support of bereaved families, of those study health visitors who had received it, the majority reported that it encouraged them to visit, gave confidence, was moderately or very helpful and should be made available to all health visitors.

Having discussed the findings relevant to the assessment tool from both the bereaved parents and health visitors point of view in Phase 2, the last chapter will discuss the findings of Phase 1 and 2, consider the implications of the research and look at the case for future research.

CHAPTER 11

DISCUSSION, IMPLICATIONS AND CONCLUSIONS

Introduction

This thesis has focused on the support of families after the sudden, unexpected death of their child (from 1 week to 12 years) from accident or illness. It did this by conducting two major studies, the first being a retrospective, quantitative study in England & Wales and the second a prospective randomised controlled trial in one health region of England.

In the first instance, Phase 1 was conducted to establish bereaved parents' perceptions of support after the sudden, unexpected death of their child, the prevailing assumption being that families were not well supported after such deaths. Chapter 2 set out the reasons why this may be the case, demonstrating that attitudes to death and bereavement in the Western world over the centuries, have changed almost with each generation, to the point now, where present society tends to deny death. By denying death, it is thus more difficult to accept the bereaved who are necessarily involved with death. The culture of individualism, segregation and fragmentation of local communities, and less involvement with established religion have also added to bereaved peoples' isolation. Whilst childhood death was common in other generations, the death of a child in today's society is fortunately a relatively rare occurrence due to better ante natal care, immunisation programmes, improved diet and better housing conditions. Children are now expected to outlive their parents, so the death of a child death is considered a

reversal of the natural order of life and thus a great tragedy. Because of its rarity, society generally is unused to such an event and therefore may not know how to behave or what to say. As a consequence, family members may be shunned, and left to cope with their grief as best they can.

The findings of Phase 1 showed that this was indeed the case. The study involved asking parents, bereaved from six months to three years, living in seven of the former regions of England & Wales, to give their opinions as to how well they had been supported both in the hospital and in the community following the death. Of 67 parents who responded, the majority reported that hospital care had been good on the whole. Although parents would have liked more choices (for instance, staying with their child as long as they wanted, washing and dressing their child and being offered mementoes), the majority reported that hospital staff had treated their children with care and dealt sensitively with the death. This was an encouraging finding and demonstrates that hospital care has improved since Finlay & Dallimore's study in 1991. It would have been interesting to have established what links hospital staff had with community staff, what procedures were taken to inform community staff of the death, and whether hospitals and the community worked together to provide a "seamless" service for the bereaved families. This would seem an area in which further research would be beneficial.

However, regardless of good or bad liaison, the study also demonstrated that parents felt isolated and unsupported both from informal and formal sources in the months after the death. They would have appreciated and also expected much more help from their G.Ps and health visitors. Whilst support from the pare ts' own family and social network may

have been lacking because of the reasons stated above and in Chapter 2, the fact that parents looked to professionals is interesting. This may be due to three factors. Firstly as support was not forthcoming from their friends and family, parents may have looked to others who might provide it. Secondly, most parents would know their G.P and health visitors prior to the death and would therefore not expect them to abandon them after such a tragedy. Edelstein (1984) noted in her study of support available to mothers, following the death of their child, that only a small percentage (18%) actively sought out support from health professionals. This would suggest that most parents' expectations of health professionals, is that they will make contact with the parents rather than them asking directly for help. Parents in Phase 1 and 2 reported that letters from their health visitors asking the parents to make contact if they wanted help were unacceptable. Sometimes the parents were unsure as to what help they required from health visitors, perceiving them as professionals who only looked after live children, in which case it could be assumed that parents were more likely to want the support of their G.P.

Parents also felt that as they were the ones undergoing severe stress, others should approach them. Thirdly, parents may now have greater expectations of the Health Service than previously. The National Health Service is based on the medical model where disease and illness are treated. Bereavement care up until now, has not been included as part of the remit of the National Health Service in a formal way, as it does not involve illness or a disease, and yet Engel suggests that bereavement "fulfils *all the* criteria of a discrete syndrome with relatively predictable symptomology and course" (Engel, 1961:18). Whether bereavement is a disease or not, it is a debilitating condition, accompanied by pain, anguish and increased morbidity. For this reason, bereaved

parents may see the role of professionals as taking away some of their pain, as pain relief is part of medical care.

Whilst assumptions can be made about why parents wanted the involvement of their primary health care team, what is apparent is that parents wanted them to be involved. Although many researchers advocate that the bereaved should be supported, no specific group of professionals has yet been identified to take on this role, other than psychologists and psychiatrists when it could be assumed that grief had become more complicated. Thus, there appeared a need to identify a group of professionals who were already in place who could make an assessment of family needs, and who could offer support from the time of death and in the months following. As was discussed in Chapter 5, although the number of voluntary bereavement agencies has grown considerably in the last decade, they may not be available or suitable for all bereaved parents, nor are they likely to make a family assessment of needs. Phase 1 showed that only 15 of 67 parents (22%) had been involved with a support group, 10 finding their support helpful and the remaining 5 not at all helpful. Paediatricians may be able to offer answers to parents' questions about causes of death and post-mortems, especially in the first weeks after a child death, and many parents in Phase 1 would have liked this opportunity. However, it is unlikely that paediatricians will have time for home visits and continued follow-up; nor may they have the skills to help a bereaved family.

Psychiatrists and psychologists may have a part to play when grief becomes complicated, but it would seem that such grief may be prevented from becoming more complex if support is provided from soon after the death. Thus it would seem

reasonable, bearing in mind the highly stressful nature of child death, that support for these families should be taken on by other professionals within the Health Service.

The aim of Phase 2, therefore, was to consider ways in which health authorities could improve support for bereaved families. The guidelines issued by the DHSS (1974), discussed in Chapter 8, point to the fact that health visitors have a definite role in considering the medical, psychological and social needs of a whole family, being constantly aware of promoting health and preventing illness. Thus it seemed that health visitors were in an ideal position for taking on support of bereaved families, especially as health visitors and G.Ps in Phase 1 showed that they felt that health visitors were suitable professionals to take on a supportive role of families whose children died suddenly. The focus of attention in Phase 2 for improving support for families was, therefore, centred on health visitors.

The Experience of Child Death- A Family Affair

However, having established that health visitors are suitable health professionals to support bereaved families, this thesis has further shown that the sudden death of a child may affect all in the close family to include parents, siblings and grandparents. The stages of grief identified by many researchers as shown in Chapter 3 can also apply to bereaved parents. However spousal grief, from which the stage theories were developed, tends to concentrate on an individual's grief and, therefore, on the intra-personal aspect only. Chapters 3 and 4 showed that each member of the close family may be affected by the death of a child in the family, that each will grieve in their own time and in their own way, sometimes leading to tensions and difficulties with relationships. Chapter 5

demonstrated that those outside the close family may also have a direct influence on the family by giving or withholding support and help. Thus, if health visitors are to offer support to bereaved families, they are required to consider all such factors within the family unit and from outside.

The Development of the Intervention

For this reason the development of an intervention to guide health visitors when supporting bereaved families was chosen. Health visitors in Phase 1 had reported that few had received bereavement training, so an intervention was devised to encourage them to continue visiting by giving them information booklets and an holistic framework based on bereavement research. The aim of the bereavement assessment tool was to guide health visitors in identification of stresses within each member (intra-personal), within the family unit (inter-personal) and from outside sources (extra-personal) so that they could plan care more easily with a view to reducing stresses wherever possible. It would appear that this is a new paradigm in approaching bereavement care.

The Booklet for Health Visitors

As discussed in Chapter 4, I had not fully understood Stroebe's dual process model at the time of writing the booklet for health visitors. I would now suggest that Stroebe's model is included alongside Worden's in the booklet to demonstrate the need for different approaches to bereaved parents and others in the family. Stroebe's dual-process model identifies two separate set of tasks, that of grieving for the person, the

primary loss, and that of grieving for the secondary losses, which for example, might mean adjusting to the role of no longer being a parent. Grieving for both may be necessary, and time away from both may be required, a different approach from that advocated by Worden (1983) where his four suggested tasks mean working through the grief constantly. Thus, differences in parents' grieving patterns at different times, may cause difficulty within the relationship which may lead to a further loss, that of the marriage. Parents in Phase 2 showed that in both groups, over half had been asked by their health visitors about their relationship with their partners since the death, which could suggest that for those parents, they may have been alerted to differences in grieving patterns and may have been relieved to have an opportunity of discussing their relationship, an area which they may have felt embarrassed to mention. Around two thirds of health visitors in each group wanted training on special needs of parents, so while the majority of parents reported that their health visitors had been supportive and caring, health visitors may need affirmation on what they are doing is satisfactory, or they may require more training in this area. It would seem that if proper supervision was available to health visitors, such difficulties could be dealt with.

Phase 2 was conducted as a randomised controlled trial to test the efficacy of the intervention. Health districts within one region of England were stratified into two groups where health visitors in one group were sent the intervention and those in the other group were not sent the intervention. The final part of this chapter will, in summary, use the findings from Phase 2 to consider future implications for the support of families whose children die suddenly and unexpectedly.

Support for Bereaved Families

In contrast to Phase 1, the majority of parents in Phase 2 perceived their support from both formal and informal sources as satisfactory. This is an encouraging finding and demonstrates that major changes have taken place in the years between Phase 1 and Phase 2, not necessarily related to the intervention.

The Use of the Intervention in Supporting Bereaved Families

Few differences were noted between the two groups of parents and their health visitors which could have biased the effectiveness of the bereavement assessment tool. The majority of parents in both groups in Phase 2 felt that their formal support had been satisfactory, reporting that they had found their health visitors caring and supportive. As was noted in Chapter 10, the average number of visits made by health visitors in Phase 2 was around five in three months, averaging around 4 hours for each family during this time, which seemed to meet the needs of most parents. Parents reported that they found it easier to talk to someone they already knew which reinforces the findings of Littlewood (1990) where professional support is perceived to be valuable if it represents a continuation of support received from professional sources prior to the death. Whilst it was found that slightly more study health visitors had asked about stresses, this would seem to have made little difference to the families. However, of those health visitors who received the intervention, nearly all would recommend its use for all health visitors. It was interesting to note that over two thirds of control health visitors wanted guidance in planning care, which would indicate that the assessment tool may be valuable for this aspect. Although control health visitors may have been guided in their care by the

questionnaire format sent to them at three months after the death, other health visitors in other parts of the country will have neither the assessment tool nor a questionnaire to guide them in the holistic and family approach. It would, therefore, seem appropriate that the intervention is incorporated into bereavement training courses.

Bereavement Training for Health Visitors

After the findings of Phase 1, it was unexpected to find that of all the health visitors in Phase 2, two thirds had received bereavement training which had met the majority's needs. The fact that so many health visitors gave good support to bereaved families in Phase 2, would seem to reinforce the value of this training. Therefore, where no such training is being offered, it is suggested that health authorities look to remedying the situation. Training, in addition to the introduction of the CESDI study into the region, may have accounted for the similarity of good support given to the bereaved families. CESDI has now been introduced to other parts of the country, which may help other health visitors with bereavement care

Another area which needs stressing in training programmes, is the care of bereaved children. Chapter 3 showed clearly that children understand death from an early age and do also grieve, usually taking cues from their parents as to how to behave. Chapter 4 showed clearly that as children take cues from their parents, the parents' role is of great importance. However parents are then faced with a daunting dual role, that of grieving for their dead child and supporting surviving children. Although not statistically significant, study mothers in Phase 2 were more anxious and depressed than control mothers. As there were 48 children from 34 families in the study group as opposed to 34

in 38 control families, the increased number of children in the study group may have accounted for the greater anxiety and depression of the mothers. Both Phases 1 and 2 showed that parents had noticed behavioural changes in their other children in the six months since the death. In Phase 2, aggressive behaviour was exhibited by more than half the children in both groups; becoming withdrawn, telling fibs, bullying others and bed -wetting were also common. Whilst many of these "disturbed" reactions may have ceased in time, they were obviously distressing to the parents, who may have believed that their children required psychiatric intervention.

However, of a total of 82 siblings, just over a quarter had been referred to other agencies. The number of referrals was slightly higher in the study group, where half of the children had been referred to bereaved counsellors. Only a small number in each group had been referred to psychiatrists or psychologists. The findings showed that over half the parents in both groups would have liked more information on helping their other children and nearly two thirds in each group would have valued more guidance. Around two thirds of all health visitors reported that they would appreciate more training on bereaved siblings. Combined with the findings from the parents, this would seem to be an area that requires further attention. As was mentioned in Chapter 10, the Childhood Bereavement Project aims to improve care for all bereaved children. As regular meetings are now being held in all regions of the country, it is suggested that health authorities are made aware of the Project so that if appropriate, professionals may attend regional meetings, and may avail themselves of this important facility. However, time to attend such meetings and travel costs may deter health authorities from allowing this, in which case there is a need for them to include the needs of grieving children in their

own courses. Although support for professionals is part of the aim of the two monthly regional meetings, this may not be sufficient for health visitors who need support at the time of caring for a bereaved family.

Support for Health Visitors

The need for proper support and supervision for health visitors has been highlighted in Phase 2. The majority in both groups of health visitors felt that their support was inadequate. Many wanted supervision to guide and help them and many also wanted a resource person to whom they could turn. The lack of proper supervision is worrying on three accounts: firstly, it means that these health professionals are not regarded as sufficiently worthy to warrant health authorities providing suitable supervision. However, as health visitors have only recently been involved in supporting bereaved families, in time, the situation may be remedied if health authorities make explicit that health visitors are there to care for bereaved families. Secondly, it leaves many health visitors concerned about the value of what they have done and whether it was right. In other professions, supervision is compulsory as discussed in Chapter 10, so it would seem a necessary requirement for health visitors also. Thirdly, there may be times when health visitors are overwhelmed by the difficulties of bereaved families who may need more intensive help than the health visitors can offer. Health visitors may be unaware that what they are doing is not necessarily helpful which proper supervision would pin-point. It would seem, therefore, that supervision for health visitors *is an urgent* requirement. Not only would this demonstrate that health visitors are valued in their contribution to supporting bereaved families, but also that bereaved families warrant care from well-supported and competent profess'onals. A resource person in each health

authority was mentioned in Chapter 8 as a possibility for helping health visitors to improve their care of bereaved families. Interestingly, many of the health visitors in Phase 2 indicated that this would be of great benefit to them. In time, this may be seen by health authorities as a necessary addition to their work force. The development of policies within health authorities to further guide health visitors would also seem appropriate

Development of Policies

There is no mention in the bereavement literature, of introducing helpful policies to guide health professionals when caring for bereaved families after a child death. As the death of a child occurs far less frequently than in past generations, most professionals will have little experience and therefore may need to be guided as to how best to help. If bereavement care is to be included in the Health Service, then I believe that each health authority should ensure that a policy is available and known. From the data collected from the health visitors in Phase 2, the majority did not know of one. For those that did, it had helped most health visitors. As was mentioned in Chapter 10, a national framework for development at local level, based on those policies which have been helpful, would seem a positive step forward.

Informal support for Bereaved Families

The importance of social support was highlighted in Chapter 5, where it was shown that social support plays an important part in the amelioration of stresses associated with various life events, and may prevent future psychological ill-health. Support may lessen

the debilitating effects of stress, and companionship may reduce the emptiness and despair associated with death. Avoidance by others of the bereaved, thus reducing social support, would seem to be a problem associated with bereavement, especially after the death of a child where anxiety and uncertainty of the social network members may cause them to fall back on such responses as "you will soon get over it" or "you can always have another baby."

It was unexpected to ascertain in Phase 2 that the majority of all parents perceived their support in the six months since the death of their child as satisfactory. It is uncertain what has brought about the improved change in informal support since Phase 1 where the majority of parents felt isolated and alone. It could be suggested that because the majority of families had good support from their health visitors, there was less need for parents to draw on other resources, and that as parents already felt supported, they may have viewed other help more positively, even when it was not necessarily forthcoming. Conversely, support from family and friends may have been sufficiently adequate, so that there was less need to rely on health visitors. Alternatively, health visitors may have helped parents sufficiently for them to ask for assistance from friends and less close family members. A fourth reason could be attributed to increased media coverage of bereavement issues over recent years. Furthermore, it would appear that the number of books on bereavement written for lay people has also increased quite markedly over the last few years. In consequence, more people generally may be aware of the difficulties of bereavement.

The death of Diana, Princess of Wales, during the second year of Phase 2, may have also helped in allowing people to grieve more openly, and to unite each other in their suffering. Her death brought forth a grief reaction that was overwhelming. Many in the nation showed open grief which may have been for Diana, a young woman tragically killed in her prime, but it may also have been for individuals' own personal grief, hitherto repressed. It could be argued that after years of denying death, as was discussed in Chapter 2, outward expressions of grief were finally being permitted. However, Merrin (1999:60) points out that on the first anniversary of Diana's death, there was barely a ripple of response from the public at large. He suggests that the day was a low key affair in which the public mood appeared at times to be one of embarrassment. The "Remembrance Walk" for Diana which was expected to feature 15,000 people, attracted only 300 (The Observer, The Review, 30th August, 1998:1). Has society then done its mourning and no longer wishes to be reminded of death? Has it reverted to the old model where grief is repressed? Only further studies will reveal whether this is the case.

The Need for Research into Minority Groups

Phase 2 has highlighted four main groups of people where little research has been conducted to look at their special circumstances. These are grandparents, ethnic minority groups, families where children die in suspicious circumstances and single parents.

Grandparents

As was seen in Chapter 3, grandparents may also be deeply affected by the death of a grandchild. They may be unable to deal with their child's grief as well as their own, and

because of the generation gap, may have different attitudes to death and bereavement which may cause relationship difficulties with the parents. Findings from the parents in Phase 2, as to whether health visitors had asked about relationships with grandparents, showed that the majority had not been asked. The number of grandparents who were offered help by the health visitors was small. The reason for this may be because many grandparents lived away from the parents, but who is to help them with their grief? Information given to the parents may improve the situation

Ethnic Minority Groups

The second group relates to ethnic minority groups. In both Phase 1 and 2, responses came from only white parents. There is a paucity of literature and research on what support is available to families from ethnic minority groups. It may be that qualitative research is more suitable for this group of people where a sensitive researcher, ideally from the same ethnic group, is able to talk to parents about their support. As Rosenblatt suggests (1993) a sensitivity to cultural differences should help prevent ethnocentric assumptions that one's own culture or experience necessarily provides a valid baseline for understanding the grief of somebody from a different cultural background. Cultures differ markedly in rules about the openness, intensity and control of anger and aggression in bereavement. Thus, assuming that angry forms of grief are transitory or unimportant because they are not common in one's own culture leaves one ill-prepared to understand the grief of people from different cultural or ethnic groups.

Families whose Children die in Suspicious Circumstances

As was shown in Chapter 9, for those families where the cause of child death may arise from non-accidental injury or even manslaughter, requiring legal intervention, there is a need to consider support for them. At present, it would seem that such families are left in isolation by professionals. Further research into this delicate and sensitive area is indicated.

Single Parents

It has been suggested by Ostfield et al (1993) that single women whose children die from cot death, are at the greatest emotional risk, experiencing higher levels of grief and reporting fewer support systems. In the study sample in Phase 2, two mothers fell into this category, each reporting that their support had been satisfactory. Of the three single men who responded, two were satisfied with their support and one felt it could have been improved.

As 40% of parents in Phase 2 were non-respondents, some of these could have been single parents. Little support and more psychological difficulties, as suggested by Keeping (1989), could have been the reasons they did not reply. It would appear, therefore, that more research, particularly qualitative research, is required for this group of parents.

Implications for Future Care of Bereaved Families

As a result of the two conducted studies, it is apparent that any future implications affect the Health Service, particularly, in improving, where necessary, the bereavement care after sudden child death offered by health authorities. The fact that health visitors in the South & West region had been given prior bereavement training, would suggest that health authorities are now recognising that health visitors are appropriate professionals for taking on this role. Where this has not been recognised in other regions, it is highly recommended that training programmes are instituted. This would seem to be a key theme emanating form this research. Training, awareness, confidence with bereaved people and acknowledgement that they are just ordinary people in extraordinary circumstances might help fight back against "modernity's" sequestration of death and the bereaved. Members of the primary health care team may all need help in overcoming the "reverse" training they get in the medical model. For this reason, it is recommended that the assessment tool especially is included in any training offered on bereavement care, particularly stressing the necessity of viewing the needs of all in the close family.

Whilst it has been used for families after the death of a child, it is suggested that the principles could be used for any family where a member has died where different generations may be affected

The need for a national framework to guide health authorities in developing their own policies for professionals would seem a requirement, and more support for health visitors involved with bereaved families is clear. In line with other professionals, as mentioned in Chapter 10, it would seem reasonable to suggest that supervision for them,

when supporting a bereaved family, is provided on a regular basis by a professional experienced in family bereavement care.

Whilst the main focus on improving care for bereaved families is on health authorities, educating the wider public on bereavement issues, particularly in relation to the needs of bereaved children, would also seem necessary. As part of the remit of the Childhood Bereavement Project is to consider education on a wide level, in time, the public generally, may have a better *understanding of the needs of bereaved children.*

Conclusions

The sudden death of a child is a devastating experience for all in the close family. Fortunately such an event is relatively rare but its rarity should alert professionals to the need for offering on-going support to the whole family in a constructive and sensitive manner, especially where support from informal social networks may be absent. This can only be assessed by making contact soon after the death.

The two studies presented in this thesis have shown that parents appreciate and need help from the health service, not only from hospital staff at the time of death but also from those working in the community. Those who suffer the unexpected death of a child have been shown to grieve more intensely and for longer than other bereavements and are already at risk from having a more complicated bereavement pattern. Unless an assessment of a family's needs is made from soon after the death, it is difficult to know which families will require more support. Health visitors have been shown to have a

vital role in visiting a bereaved family soon after the death, in assessing their particular needs and stresses and in continuing to visit in the months after the death. Such support may alert and encourage others in the local social network to offer informal help and the combination of both types of support, both informal and formal, may prevent referral to more specialist professionals at a later date when grief has become more complicated.

Whilst the intervention was not used directly with families by 40% of the study health visitors, nearly all felt that it could be of use to other health visitors and should thus be made available. This would suggest that the information provided in the assessment tool and the booklet may have been of value in understanding bereavement support better.

Only further studies will reveal whether those in Phase 2 recovered more quickly and easily because their health visitors were there to support them. If this is proved, then the preventive role of health visitors would be truly recognised.

Sadly since this study was completed, other families throughout the country will have suffered the death of their child and others will experience such an event in the future. Such families deserve the very best of our professional knowledge. Whilst those in Phase 2 may have been reasonably satisfied with their support, there is no guarantee that other families will feel likewise. Therefore, it is important that, what has been found in these two major studies, is widely publicised so that health authorities may be guided to provide a supportive service, so that in turn, those who suffer such a tragedy may at least feel that society cares.

APPENDIX 1

PHASE 1: PARENTS' QUESTIONNAIRE

RECORD NO.

BEREAVEMENT CARE IN ENGLAND AND WALES FOR FAMILIES AFTER THE SUDDEN AND UNEXPECTED DEATH OF AN INFANT OR CHILD

PARENTS QUESTIONNAIRE

Contact Address :

Mrs Ann Dent & Mrs Louise Condon,
Bereavement Project,
Dept of Child Health,
St Michael's Hospital
Southwell St,
Bristol BS2 8EG.

Tel : 0272 285356

Every experience of a child death is different and, whilst some of these questions will be appropriate to you, others may seem less so. The questionnaire is divided into sections, some of which may not apply to you. In this case you should go on to the next section. We would be grateful if you could help us by answering as many of these questions as possible but if there are any questions you don't want to answer, just leave them blank.

We would really appreciate any comments you may want to write at any point in the questionnaire.

We appreciate that by filling in this questionnaire you may be reminded of very painful memories. We suggest that you set aside time and quiet, if possible, to complete the questions, asking for the help of a close friend if this is appropriate.

Because of the confidentiality of this study it would be helpful if surnames and dates are <u>not</u> written on any part of this questionnaire. If any are accidentally given they will be removed to prevent identification.

Please indicate who is filling in this questionnaire:

Mother .....

Father .....

Partner .....

Other (specify) .....

.....

(Please tick the appropriate answer)

SECTION A

The first section is asking you to give some information about your child.

1. How old was your child when she died?

..... Years ..... Months

2. How long ago did your child die?

..... Years ..... Months

3. What was the cause of her death?

4. Where did your child die?

	Yes	No
At home	.....	.....
In hospital	.....	.....
Other (please describe)	.....	.....

.....

If in hospital, please say where:

Accident and Emergency Department/Casualty .....

Intensive Care .....

Children's Ward .....

Other (please describe) .....

5. a) Were you with your child when she died?

Yes	.....
No	.....

b) Was anybody else there?

	Yes	No
Partner	.....	.....
Doctor	.....	.....
Nurse	.....	.....
Ambulanceman/woman	.....	.....
Policeman/woman	.....	.....
Fire officer	.....	.....
Other (please specify)	.....	.....

.....

SECTION B

This section is asking you about the services immediately called to help. If the emergency services were not called, please go on to Section C on page 6.

1. a) When it was found that there was something seriously wrong with your daughter were any of the following services called? (please tick whichever is applicable)

	Yes	No	Don't know
Ambulance	.....	.....	.....
Police	.....	.....	.....
Fire Brigade	.....	.....	.....
Your doctor	.....	.....	.....

b) If yes, how satisfied were you with the time the service took to arrive?

	I was dissatisfied	I am unsure	I was satisfied
Ambulance	.....	.....	.....
Police	.....	.....	.....
Fire Brigade	.....	.....	.....
Your doctor	.....	.....	.....

c) When they arrived, how satisfied were you with the service?

	I was dissatisfied	I am unsure	I was satisfied
Ambulance	.....	.....	.....
Police	.....	.....	.....
Fire Brigade	.....	.....	.....
Your doctor	.....	.....	.....

2. What parts of their service, if any, did you particularly appreciate? (Please describe)

Ambulance:

Police:

Fire Brigade:

Your doctor:

3. What else could they have done to improve the service? (Please describe)

Ambulance:

Police:

Fire Brigade:

Your doctor:

4. Were you given the opportunity to accompany your child in the ambulance to hospital?

Yes .....

No .....

Not applicable .....

SECTION C

These questions are about the hospital and the service you received. If your child was not taken to hospital please go on to Section D on page 8.

1. How would you describe the service provided by the hospital?

(Please tick which ever is applicable)

	very good	good	average	bad	very bad	don't know
Care of your child	.....	.....	.....	.....	.....	.....
Communication	.....	.....	.....	.....	.....	.....
Helpfulness	.....	.....	.....	.....	.....	.....
Efficiency	.....	.....	.....	.....	.....	.....
Facilities for Relatives	.....	.....	.....	.....	.....	.....

2. How would you describe the care you received from the following staff?

(Please tick that which is applicable)

	very good	good	average	bad	very bad	don't know
Doctors	.....	.....	.....	.....	.....	.....
Nurses	.....	.....	.....	.....	.....	.....
Receptionist	.....	.....	.....	.....	.....	.....

3. What else could the staff have done to help you?

4. a) Were any of the following available to you in hospital?

	Yes	No
A quiet place to sit	.....	.....
A private room	.....	.....
Information about what was happening	.....	.....
A member of staff to sit with you	.....	.....
Refreshments	.....	.....
Play area for children (if present)	.....	.....
Access to a telephone	.....	.....
Transport home	.....	.....

b) What would you have liked to have had available? (please describe)

SECTION D

This section asks about what happened immediately after your child died.

1. a) Did anyone tell you or confirm that your child had died?

Yes	.....
No	.....

(If No, please go on to Section E on page 10)

b) If yes, who was this?

	Yes	No
Partner	.....	.....
Another relative (please say who)	.....	.....
.....		
Doctor	.....	.....
Police officer	.....	.....
Other (please say who)	.....	.....
.....		
Don't know	.....	.....

c) We would be grateful if you could comment on the way that you were told, about your daughter's death :

(i) Do you remember the words used?

Yes .....

No .....

(ii) Would you prefer to have been told in a different way?

Yes .....

No .....

(iii) Please comment on the way in which you were told?

SECTION E

This section is asking you about the choices you were given about the care of your child after death and how you feel about them now. We realise that if your child's body was badly damaged some of the questions may not be appropriate. Please leave these blank.

1. After the death of your daughter were you offered the opportunity to:

(Please tick the most appropriate answer)

a) See her :

Yes, and did see .....

Yes, but did not see .....

No .....

Not applicable .....

If no, would you like to have done this?

Yes .....

No .....

Not sure .....

b) Touch her :

Yes, and did touch .....

Yes, but did not touch .....

No .....

Not applicable .....

If no, would you like to have done this?

Yes .....

No .....

Not sure .....

c) Hold her :

Yes, and did hold .....

Yes, but did not hold .....

No .....

Not applicable .....

If no, would you like to have done this?

Yes .....

No .....

Not sure .....

2. a) Did the hospital staff explain to you that you could do any of the following?

	Yes	No	Don't know	Not applicable
Stay with her as long as you wanted to	.....	.....	.....	.....
Wash her	.....	.....	.....	.....
Dress her in her own clothes	.....	.....	.....	.....
Accompany her to the mortuary or chapel of rest	.....	.....	.....	.....
Bring relatives to see her	.....	.....	.....	.....
Bring other children to see her	.....	.....	.....	.....
Take her body home with you	.....	.....	.....	.....

b) If any of the above were NOT offered, do you now wish that they had been?

Yes .....

No .....

c) If yes, please specify:

3. a) Were you offered any of the following :

	Yes	No
Photograph of your child	.....	.....
Handprint	.....	.....
Footprint	.....	.....
Lock of hair	.....	.....
Other (please describe)	.....	.....

b) If some/all of these were NOT offered do you now feel that you would have liked these?

Yes .....

No .....

c) If yes, please say which:

4. a) When your child's belongings were returned to you was this done with sufficient consideration of your feelings?

Yes .....

No .....

b) If no, what would you have preferred?

5. a) Did anyone discuss organ donation (eg kidney, cornea, etc.) with you?

Yes .....

No .....

Not applicable .....

b) If yes, do you think this was done in a sensitive way?

Yes .....

No .....

Not applicable .....

c) If organ donation was not suggested to you, would you liked to have been asked?

Yes .....

No .....

Not sure .....

Not applicable .....

6. Were you given any of the following by the hospital?

Helpline telephone number .....

Leaflets for bereaved parents .....

Contact number for support group .....

Other (please describe) .....

SECTION F

This section asks you about the coroner's officer/police. If you had no involvement with either of these, please go on to Section G on page 16.

1. a) Did the police or coroner's officer ask you to identify your child's body?

Yes .....

No .....

b) If yes, do you think that this was done in a sensitive way?

Yes .....

No .....

Not sure .....

2. a) Did the police or coroner's officer take away clothing or bedding?

Yes .....

No .....

b) If yes, were you offered it back?

Yes .....

No .....

3. a) Did the police or coroner's officer collect information from you about the circumstances of the death?

Yes .....

No .....

b) If yes, do you think this was done in a sensitive way?

Yes .....

No .....

Not sure .....

SECTION G

This section is about the press. If the press were not involved at all please go on to Section H on page 17.

1. a) Did any of the following happen : (please tick whichever applies)

	Yes	No	Don't Know
Newspaper report(s) of your child's death	.....	.....	.....
Television report(s) of your child's death	.....	.....	.....
Radio report(s) of your child's death	.....	.....	.....
Reporter(s) coming to your house	.....	.....	.....
Reporter(s) telephoning you	.....	.....	.....
Other media contact (please say which)	.....	.....	.....

.....

b) If yes, please describe how this affected yourself and your family :

SECTION H

This section asks about letting government departments know about the death of your child.

1. a) Were you given any information about how to register the death (such as where to go and how soon after the death)?

Yes	.....
No	.....

b) If yes, who gave you this information? (Please tick as appropriate)

	Yes	No
Relative (please say who)	.....	.....
Your doctor	.....	.....
Hospital staff (please say who)	.....	.....
Health visitor	.....	.....
Social worker	.....	.....
Other (please say who)	.....	.....

2. Who registered your child's death?

	Yes	No
Yourself	.....	.....
Partner	.....	.....
Relative (please say who)	.....	.....
Other (please say who)	.....	.....

3. a) Were you given any information about letting the DHSS know that your child had died?

Yes	.....
No	.....

b) If yes, who gave you this information?

	Yes	No
Relative (please say who)	.....	.....
Health visitor	.....	.....
Social worker	.....	.....
Other (please say who)	.....	.....

4. a) Was there anything upsetting about the way the DHSS withdrew child benefit?

Yes .....

No .....

b) If yes, please describe:

SECTION I

This section is about the post mortem. If there was no post mortem please go on to Section J on page 22.

1. How many days after your child's death was the post-mortem carried out?

Number of days : .....

2. Who first told you of the findings of the post-mortem?

	Yes	No
Not informed	.....	.....
Your doctor	.....	.....
Paediatrician	.....	.....
Coroner Staff	.....	.....
Other (please say who)	.....	.....

.....

3. a) Did you find the explanation of the findings clear enough for you to understand?

Yes .....

No .....

Don't know .....

Not applicable .....

b) Were you given the chance to ask questions?

Yes .....

No .....

Don't know .....

Not applicable .....

c) Were your questions answered to your satisfaction?

Yes .....

No .....

Don't know .....

Not applicable .....

d) If you were not satisfied with the answers to your questions, why was this?

SECTION J

This section asks you about the funeral.

1. a) Do you feel that your child's body (between death and the funeral) was cared for with the respect that you would have liked?

Yes .....

No .....

b) If no, why not?

2. a) Did anyone discuss with you how to make funeral arrangements?

Yes .....

No .....

b) If yes, who was this?
(Please tick as appropriate)

	Yes	No
Your doctor	.....	.....
Hospital staff (please say who)	.....	.....
Health visitor	.....	.....
Social worker	.....	.....
Paediatrician	.....	.....
Health Visitor	.....	.....
Other (please say who)	.....	.....

3. a) Did you involve a funeral director in arranging the funeral?

Yes .....

No .....

Not applicable .....

b) If yes, were you satisfied with the help provided?

Yes .....

No .....

Not sure .....

Not applicable .....

4. a) Did you involve a minister of religion in arranging the funeral?

Yes .....

No .....

Not applicable .....

b) If yes, were you satisfied with the help provided?

Yes .....

No .....

Not sure .....

Not applicable .....

5. a) Were you satisfied with your child's funeral service?

Yes .....

No .....

Not sure .....

Not applicable .....

b) If no, why was this?

SECTION L

This section asks you for information about any support given in your bereavement.

1. Please indicate whom you have talked to about the death of your daughter, and how helpful this has been :

   (Please tick as many as are applicable)

	Discussed With	Found it very helpful	Found it quite helpful	Found it not at all helpful
Your doctor	.....	.....	.....	.....
Hospital Doctor	.....	.....	.....	.....
Paediatrician	.....	.....	.....	.....
Nurse	.....	.....	.....	.....
Health Visitor	.....	.....	.....	.....
Midwife	.....	.....	.....	.....
Social worker	.....	.....	.....	.....
Minister of religion	.....	.....	.....	.....
Local support group	.....	.....	.....	.....
Other (please describe)	.....	.....	.....	.....

.....

2. a) Have you been back to the hospital to talk about the death of your child with a hospital doctor?

   Yes .....

   No .....

   b) If no, would you like to have done this?

   Yes .....

   No .....

   Not sure .....

   Not applicable .....

   c) If you have discussed your child's death with a doctor, did you find the meeting helpful?

   Yes .....

   No .....

   Not sure .....

3. a) Have you received bereavement support from a health professional?

   Yes .....

   No .....

   b) If yes, who from?

(Please tick as appropriate)	Yes	No
Your doctor	.....	.....
Health Visitor	.....	.....
Social worker	.....	.....
Bereavement counsellor	.....	.....
Community psychiatric nurse	.....	.....
Psychiatrist	.....	.....
Psychologist	.....	.....
Other (please say who)	.....	.....

.....

c) How many meetings have you had?

.....

d) Did you find these meetings helpful?

Yes .....

No .....

Not sure .....

4. In general, how do you feel about the information/advice that was given to you about the following:

(Please tick which ever are applicable)

		Too much	Too little	Just right	No information given
a)	How to contact support groups	.....	.....	.....	.....
b)	Follow up care at hospital	.....	.....	.....	.....
c)	Post-mortem	.....	.....	.....	.....
d)	Funeral/memorial services	.....	.....	.....	.....
e)	Registration of death	.....	.....	.....	.....
f)	How to help your other children	.....	.....	.....	.....
g)	other (please describe)	....	....	....	....

.....

5. a) Were you given or sent any information leaflets from support groups?

Yes .....

No .....

Don't know .....

b) If yes, did you find them helpful?

Yes .....

No .....

Don't know .....

c) What did you find particularly helpful?

d) What improvements could be made?

6. a) Have you had contact with a local support group concerned with bereavement?

Yes (please say which) .....

.....

No, but would have liked to .....

No, I did not want to .....

b) If yes, who told you about it?

	Yes	No
Casualty	.....	.....
Your doctor	.....	.....
Health Visitor	.....	.....
Paediatrician	.....	.....
Head office of support group	.....	.....
Other (please describe)	.....	.....

.....

Don't know	.....	.....
Not applicable	.....	.....

SECTION M

This section asks about the help and support you feel you have been given.

1. Please let us know how you feel about the following:

(Please tick the appropriate answer)

		I often feel like this	I sometimes feel like this	I never feel like this
a)	My partner provides the emotional support I need	.....	.....	.....
b)	There are other parents who have suffered the death of a child with whom I can share my experiences	.....	.....	.....
c)	There is always someone I can share my feelings with	.....	.....	.....
d)	I have no one to share my feelings with	.....	.....	.....
e)	Since this happened my relationship with my partner has been quite strained	.....	.....	.....

2. Which health professional has been of most help to you and why?

3. Which other person has been most helpful to you since your child's death and why?

SECTION N

This section asks about other children in the family. If you have no other children please go on to Section O on page 34.

1. Please give details of your children

Sex	Age	Who told them of their sister's death (yourself, partner, grandparent, your doctor, friend, etc)
....	....	.....
....	....	.....
....	....	.....
....	....	.....
....	....	.....
....	....	.....
....	....	.....

2. Since the death has the behaviour of your child/children changed in any of the following ways?

	Yes	No
Becoming withdrawn	.....	.....
Unable to concentrate	.....	.....
Bed-wetting	.....	.....
Being bullied	.....	.....
Bullying other children	.....	.....
Telling lies	.....	.....
Aggressive behaviour	.....	.....
Stealing	.....	.....
Other (please describe)	.....	.....

.....

3. a) Have any professionals given you any information about how best to help brothers or sisters?

Yes	.....
No	.....
Not sure	.....

b) If yes, who was this?
(please tick as many as applicable)

	Yes	No
Your doctor	.....	.....
Paediatrician	.....	.....
Health Visitor	.....	.....
Social worker	.....	.....
Bereavement counsellor	.....	.....
School staff	.....	.....
Other (please describe)	.....	.....

.....

c) Have you found this information useful?

Yes	.....
No	.....
Don't Know	.....

d) If no please could you tell us why?

4. a) Have your children received bereavement support from a health professional?

Yes .....

No .....

b) If yes, who from?
(please tick as many as applicable)

	Yes	No
Your doctor	.....	.....
Health Visitor	.....	.....
Social worker	.....	.....
Bereavement counsellor	.....	.....
Community Psychiatric Nurse	.....	.....
Psychiatrist	.....	.....
Psychologist	.....	.....
Other (please say who)	.....	.....

.....

5. a) Do you think health professionals could have helped more with your children?

Yes .....

No .....

Don't know .....

b) If yes, please describe in what way.

SECTION Q

The final section is about yourself. We ask these questions to find out what care is given to different families in different parts of the country.

Please tick the appropriate answer to each question.

1. How old were you on your last birthday?

..... years

2. What is your present marital status?

Married .....

Living together .....

Widowed .....

Separated .....

Divorced .....

Not married and not living together .....

Don't know .....

3. What is your highest educational qualification?

Degree or equivalent .....

Higher education below degree (including nursing) .....

A level or equivalent .....

O level or CSE grade 1 or GCSE grades A-C .....

CSE (other grades) and commercial qualifications .....

Foreign or other qualifications .....

No qualifications .....

Don't know .....

4. What is your usual occupation? (Please give an exact description)

5. Are you currently employed?

Yes .....

No .....

6. How would you describe your religion?

Catholic .....

Protestant .....

Jewish .....

Hindu .....

Muslim .....

Buddhist .....

Agnostic .....

Atheist .....

Other (please describe) .....

.....

None .....

Don't know .....

7. Which of the following best describes your ethnic group?

White .....

Black-Caribbean .....

Black-African .....

Black-other .....

Indian .....

Pakistani .....

Bangladeshi .....

Chinese .....

Other (please describe) .....

.....

8. a) Type of housing?

Detached .....

Semi-Detached .....

Terraced .....

Purpose built flat .....

Converted flat/room .....

With business premises .....

Other (Please Specify) .....

.....

b) What is the council tax band of your accommodation

A	.....
B	.....
C	.....
D	.....
E	.....
F	.....
G	.....
Not applicable	.....
Don't know	.....

Finally, we would be grateful if you could tell us what advice you would give to health professionals who work with bereaved parents?

If you have any further comments to make about your experience or about the questionnaire itself, please write them below. If there is not enough room please attach another sheet of paper.

Thank you for completing this questionnaire. Your help will enable us to assess the support that parents receive nationally in order to improve it where necessary.

Would you be willing to let us contact you in the future if we need some more information?

Yes	.....
No	.....

APPENDIX 2

THE INTERVENTION USED IN PHASE 2:

BOOKLET FOR BEREAVED PARENTS
BOOKLET FOR HEALTH VISITORS
THE BEREAVEMENT ASSESSMENT TOOL

WHAT IS BEREAVEMENT?

GUIDELINES FOR PARENTS WHEN THEIR CHILD DIES SUDDENLY AND UNEXPECTEDLY

WHAT IS BEREAVEMENT?

GUIDELINES FOR PARENTS AND THEIR FAMILIES WHEN THEIR CHILD DIES SUDDENLY AND UNEXPECTEDLY

The death of a child must be one of the worst tragedies for a a family to experience. When a child dies suddenly and unexpectedly, there is no preparation, no warning, so the shock is overwhelming. You may feel shocked for several weeks following the death, just at a time when you need to make important decisions. Once the funeral is over, you have the difficult task of carrying on with your life when you ache inside for your dead child.

Bereavement is about living with the pain, working through the feelings you may have of anger, guilt, anxiety, sadness and depression. It is right that you should grieve for your child because your child was a part of you, yet unique and special. Right now, it is difficult for you to believe that life will ever be good again, and that you will smile, laugh and enjoy yourself once more. Bereavement, at first, is like an open wound, raw and painful, but just as a wound eventually heals, so will your pain. This does not mean that you will ever forget your child or love your child any less.

WHAT WILL YOU EXPERIENCE?

Because each of us is unique, we all grieve differently. What is right for you may not be right for your partner, but most people will experience some or all of the following feelings, but not necessarily at the same time.

When death is so sudden, it is difficult to believe that it has actually happened. Once the shock has worn off, you may experience a great need to look for and find your child, although deep down, you are beginning to realize that your child has died. Because you are constantly searching, it is hard to relax or concentrate and you may have difficulty in sleeping. Dreams may be extremely disturbing. You may even hear your child's voice. Do not be afraid to take some time off work. This does not mean that you are weak, but such a crisis means that you need time to recover.

People often feel real ANGER at this time, towards doctors and nurses who did not prevent the death, towards friends and relatives who did not or are not doing enough, or even towards their God if they have a faith.

Another common feeling is GUILT. You may find yourself going over in your mind all the things you would liked to have said or done. You may consider what you could have done differently that might have prevented the death. It is worth remembering that death is beyond anyone's control. Try writing down all the thoughts that you have had that make you feel guilty, until the pain begins to ease.

You will probably find that there will be times of quiet sadness or depression when you find it hard to talk to others. Periods of depression tend to become more frequent and you may experience spasms of grief, sparked off by people, places or things that remind you of your dead child. It is quite natural that you will have sudden outbursts of crying, so that you may be tempted to avoid other people. During this time it may seem to

others as though you are spending a lot of time just sitting doing nothing but this is an important part of helping you to accept your child's death.

As time passes and this probably takes months, depression lessens and it is possible to think about other things and even to look forward to the future. However, the sense of having lost a part of yourself will never go away entirely, although it is possible to feel whole again, but in a different way from before.

RELATIONSHIPS

Partners

It is difficult to help each other when you have both been so badly wounded. Anger can often be directed towards each other because your feelings are so intense and you are unable to stand back and see what is happening. If you have other children, there is the added strain of how to help them. It is helpful if you can share your feelings with each other, although this can be difficult at first. Try to be patient with yourself and each other, remembering that because you are each unique, you will not both feel the same at the same time. It may be difficult to stay in touch physically but hugging and touching are important. Try when possible to do things together.

Grandparents

Like you, they will feel helpless and hurt and will have their own grief to bear, similar but different to yours. Even if the grandparents were not close to your dead child, they will see you, their own child in great pain. They may have ideas that don't match with yours, but try to talk things through with them so that they understand your feelings, and you can understand theirs. There are leaflets available to help grandparents which you can obtain from your health visitor.

If you have other children

It is important to recognise that children grieve too and have feelings similar to adults. Even little children under two will feel confused and bewildered by what is happening around them. Even if they do not understand words they will be affected by the death, because they see your sadness and feel your pain. You may want to protect your children by not involving them in discussions or the funeral, but they will benefit from being involved and having time with you to help them with their own feelings of anger, guilt and sadness. Sharing tears is good for you and them. Like you, your children will appreciate honesty and being listened to. It is worthwhile giving them information gradually and allowing time for it to sink in. For a while you may find that they will bed-wet, have difficulty in concentrating and become quite clingy. They may even resort to bullying at school, of becoming sad and withdrawn and even allowing themselves to be bullied. This is understandable as they are greatly distressed too. If your children are at school, do talk to their teachers and share with them your concerns which may be theirs as well.

Friends and other relatives

You may find that other people will avoid you, not because they don't care but because they have no idea of what to say or how to behave, because they believe they may upset you further by saying the wrong thing and because they are unsure of what to do if you become tearful or if they break down. Sometimes your loss may remind others of something painful that happened to them in the past.

Just when you need all the support you can get, people will shy away from you. Sadly you may have to take the first step in mentioning your child's death to them so that they can feel more comfortable.

It is worth remembering that:

* Grief is a natural reaction to loss. It is right that you should grieve and express your feelings.

  ANGER, GUILT, SADNESS & DEPRESSION are part of bereavement. You may have these feelings at different times from your partner or children.

* Grieving takes at least 2 years, so don't be put off by others who think you should have recovered after 6 months.

  The pain will not always be as intense as it is at first and as the weeks go by, it will get less.

* Each of you in the close family will be affected by the death. You can help each other by sharing feelings. Children will benefit from being listened to.

* Your health visitor and G.P. are there to help, so do ask them about anything that worries you. There are also support groups of other bereaved parents who will be very willing to help too.

  If you would like to know more about bereavement, there are many leaflets available which you can get from your health visitor.

Suggested Books for parents

1. Sarnoff Schiff H.,"The Bereaved Parent",Souvenir Press,London 1977

2. Wells R.,"Helping Children Cope with Grief",Sheldon Press,London, 1988

3. Grollman E.,"Explaining Death to Children",Beacon press,Boston,1967

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Books ordered will be sent, within 48 hours.

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Tel: 0171 247 0617

CRUSE
(Offers leaflets and counselling)
126 Sheen Road, Richmond, TW9 1UR
Tel: 0181 940 4818

Compassionate Friends
(Offers befriending, support groups and leaflets)
53, North Street, Bedminster, Bristol BS3 1EM
Tel: 0117 9539 639

SANDS
(National helpline for parents and professionals and support through group network)
28 Portland Place, London WIN 4DE
Tel : 0171 436 5881

Child Bereavement Trust
(Training for professionals, resources for families)
Tel : 01494 765001

GUIDELINES FOR HEALTH VISITORS

BEREAVEMENT CARE FOR FAMILIES WHOSE CHILD HAS DIED SUDDENLY AND UNEXPECTEDLY

BEREAVEMENT PROJECT

Project Leader:
Mrs Ann Dent
Tel: 0117 928 5356

BEREAVEMENT CARE FOR FAMILIES WHOSE CHILD HAS DIED SUDDENLY AND UNEXPECTEDLY

GUIDELINES FOR HEALTH VISITORS

Introduction

Research now shows that the sudden, unexpected death of a child is one of the most painful life experiences for families to endure. Supporting such families is not an easy task, requiring sensitivity and understanding. Because many of us feel inadequate and are fearful of failing, we do not risk visiting but the families will appreciate our presence which in itself shows we care.

The assessment tool has been designed to help you in planning care. It is divided into sections with suggested topics in each to guide you in identifying stresses within the family which may be physical, psychological, socio-cultural, or spiritual. All four areas can be affected in the course of bereavement. These notes are designed to accompany the assesment tool.

It should be stressed that no two families are the same so each family will have different needs at different times. However, common to all families when a child dies suddenly and unexpectedly, will be any lack of preparation for the death, leaving close family members shocked and bewildered.

Most of all, grieving people need someone to care, someone who will listen and help them to work through their grief. Simple words such as "I am so sorry", whilst seeming inadequate, are all we have. Our body language will show our care and concern.

It is not sufficient to chat idly over a cup of coffee. Parents should be encouraged to work at their grief with your help. Most grieving people have little knowledge of the process of grief and probably have no idea why you have come, as their child has died. It is therefore important that you explain from the outset,that you are there to care for them, to help them work through their grief and to help them adjust to their loss. The frequency of your visits will depend on their needs. Any visit should not last more than an hour as this is sufficiently long for parents to talk of their pain, and for you to listen attentively.

Psychological Effects

Anger and guilt are common feelings experienced by the bereaved, especially parents whose child has died suddenly and unexpectedly. It is important to establish what has caused these feelings and to enable parents to talk of them repeatedly. In doing so, healing will start. Parents are sometimes reticent to mention their strong feelings for fear of being judged, but in a safe environment with a trusted carer, there will be more opportunity for talking of them. Anger may well be directed towards others who have been seen as failing in not keeping their child alive, not getting to the child in time, giving poor service, not being offered choices, being insensitive or not carrying out the parents' wishes. Sometimes it is easier to blame others and stay with the positive feeling that anger evokes. Some anger will be justified when parents will appreciate honest answers and explanations. Other parents will not necessarily require answers but an opportunity to express their angry feelings.

"If only I had, hadn't ...." are common expressions of guilt. Reassurance is not always reassuring and the best way to deal with guilt is to acknowledge it and encourage parents to talk about it as often as they feel the need.

Depression is a natural reaction to a severe loss, usually occuring some months from the death and lasting longer than most parents imagine. It is difficult to help someone who is depressed as for them everything seems negative and useless. It is important that you stay with their feelings at this time and allow the depression to take its course. The thought of suicide is not uncommon. Do not be afraid to ask if they have had thoughts about this. (If there is any real danger to their lives then you should share such information with the G.P.)

It may be useful for them to write down their feelings from day to day and to discuss these feelings at each visit.

If there has been a history of depression before the death, then specialist help may be required.

During your assessment, it is important to ask about other significant deaths or losses, as there may still exist powerful, unexplored feelings which may block the feelings surrounding the recent death. If this is the case, then you may need to talk of them before dealing with the present loss.

Establishing the sorts of relationships that exist amongst close family members will help in identifing any particular stresses Ideally, it is good if all family members can be open and honest with each other, sharing their feelings with younger and older members.

Physical Effects

Because sleep and appetite are almost always affected after a sudden bereavement, general health is at risk. Constant tiredness can be a problem so that even the smallest task becomes an effort. Parents may require extra practical help in the first few weeks, especially if there are other children.

When a baby has died whom the mother was feeding, attention may be needed to ensure that her breasts are comfortable.

Some bereaved siblings may show their distress in disturbed sleep patterns and in bed-wetting, or by being very clingy. This will put an added burden on the parents, requiring understanding, love and patience from them, at a time when they are already stretched.

Socio-Cultural Issues

Each family will have its own way of dealing with death and mourning, which may not be open. Encouraging parents to consider other options, by giving them the information leaflet and thinking through issues with them, will give them an opportunity of choosing for themselves. Sometimes they may need permission to do it their way. Whatever they choose should be respected.

Many parents will find that friends and family may avoid them, not because they don't care but because they are unsure as to what to say and how to behave. Parents may need to be helped to take the initiative in approaching them.

When meeting with a family from a different culture, sensitivity to their needs is required so that they are not offended. It is worth finding out about the particular rituals and traditions from a representative before visiting. Where English is not the first language, an interpreter may be required.

Spiritual Issues

Spiritual does not necessarily mean religious. It relates to a concern with ultimate issues and life values and is often seen as a search for meaning. Religious relates more to the expression or putting into practice of spirituality such as a desire to see a priest, to receive Holy Communion or to attend services. All of us have spiritual needs, heightened by a death, especially the death of a child. Some parents may wish to talk to a priest or may choose to talk to you about their feelings about death, mortality or an after life. Some parents may wonder where their child is now.

Those with a faith may gain great solace or alternatively may reject it in anger, as their God (or Higher Being) has caused pain and suffering.

Working through Bereavement

Worden describes 4 tasks for the bereaved to work through:

(i) accepting the reality of the death

(ii) experiencing the pain of grief

(iii) adjusting to an environment in which the deceased is missing

(iv) withdrawing emotional energy and reinvesting it.

Accepting the Reality

Because there is no warning, it is harder for parents to accept that the death has actually happened and their child will never be alive again. The shock of such an experience may last for several weeks so that accepting that the death occurred and working through different feelings may take some time. All members of the close family will be affected, and should not be seen in isloation but as an integral part of that family, with its own dynamics, strengths and weaknesses. In helping parents accept the death as a reality, it is important to use the dead child's name along with such words as "dead" or "has died." It is hoped that the hospital staff have given the parents choices such as seeing and holding, washing and dressing their child or baby, which will reinforce the fact that the child has died. It is difficult to accept that someone has died without seeing the dead body. Mementoes of the dead child, such as photographs, locks of hair and foot or hand prints can bring much comfort in the years ahead and give positive reminders of the dead child, although not all parents will want them at the time of death. Putting mementoes in the coffin also can give comfort. It is also important that all close family members have the chance to say good-bye to the dead child, both in the hospital and at the funeral. This includes siblings and grandparents.

Experiencing the pain of grief

As each family will have different needs, so will each member of a grieving family. It is easier and more acceptable for mothers to cry. Many fathers may want to be strong for their families and in doing so, may hide their true feelings of pain to avoid breaking down. Parents should be encouraged to share their feelings with each other, with siblings and grandparents. It is good that children see their parents cry as this affirms for them the worth of their brother or sister, and allows them the opportunity of crying too. Children, like adults, benefit from being listened to and may want to talk of their feelings of guilt and anger. If at all possible, the parents should be encouraged to listen and share. If they feel unable to do this then grandparents or other well known family members or friends may be willing to help. Both adults and children may find it helpful to write down their feelings, or make an album together of the dead child. Children may find it easier to draw pictures which can be discussed with the parents.

Adjusting to an Environment without the deceased

As the months go by, there will be days when things seem lighter. Parents may start to feel like laughing again, enjoying themselves, but then feel guilty that for a while they have forgotten their dead child. It is difficult for them to know when they should stop grieving and start to live pleasurably again.

It is good to encourage them to return to some sort of normality. Life will never be the same but it can still be good.

Anniversaries and birthdays are difficult days, which can be planned ahead if that is what the parents choose. It is worth considering sending a card on the anniversary of the death.

Withdrawing Energy and Reinvesting it

Detachment does not mean that parents will not go on loving their dead child, but can love others too in a different way. Some parents may feel that by withdrawing emotional attachment, that they are somehow dishonouring the memory of the dead child. Others may fear that by investing love in others that they may lose them too.

Care for Yourself

Bereavement visiting is tiring and demanding. Listening intently requires great concentration, and seeing and hearing someone's mental anguish and despair can take its toll on your resources., Be aware of any pain that you may feel from losses of your own. Try to share it, and other feelings surrounding the bereavement with a trusted colleague or friend. Be gentle and kind to yourself and allow space for reflection and relaxation.

For Further Reading:

1. Worden,J.W.,"Grief Counselling &Grief Therapy" ,Tavistock Publications,London & New York,1983

2. Sarnoff Schiff,H.,"The Bereaved Parent",Souvenir Press,London 1977

3. Stewart A.,Dent A.,"At a Loss - Bereavment care when a Baby dies",Bailliere Tindall,London,1994

4. Raphael B.,"The Anatomy of Bereavement",Routledge, London, 1984

Suggested Books for parents

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BEREAVEMENT

ASSESSMENT TOOL

Bereavement Project
Project Leader:
Mrs Ann Dent
Tel: 0117 928 5356

BEREAVEMENT ASSESSMENT TOOL FOR HEALTH VISITORS

GUIDELINES - PLEASE READ CAREFULLY BEFORE USE

The assessment tool belongs to the health visitor and the family and will not be required by the researcher.

It is suggested that the tool is not used until after the first visit after the death.

From the outset, it is vital that emphasis is placed on parental input and that the health visitor and the family work together to plan care.

Space is provided in the form for the health visitor to enter comments on any areas which require further discussion.

Once the assessment has been completed, the health visitor is required to prioritise which areas need to be dealt with.

A list of the main headings is provided on the back sheet.

At the next visit, the care plan should be shared with the family to check that the health visitor's perceptions are correct, and then put into action with the family's approval.

FAMILY BEREAVEMENT ASSESSMENT FORM

Family Name(s) .....

Ist Names of Mother & Father ....

Address(es) .....

.....

Tel.no(s) .....

Name of Child Who Died ..... Age .....Yrs .....Mths

Cause of Death (If Known) .....

Date of Death ...../...../..... Hospital Where Child Died .....

Names of Other Children (If Any)	Ages	Schools (where appropriate)
.....	.....	.....
.....	.....	.....
.....	.....	.....
.....	.....	.....

G.P. .....

NB **The following questions are for guidance only. You may want to ask other questions as well.**

ABOUT THE DEATH

How were the parents told about the death? Were they present at the death? Did the hospital staff give good care before the death? Were the parents kept fully informed as to what was happening while their child was being treated before the death? Were they satisfied with the Emergency Services? Were they satisfied with the care given by religious leaders?

AFTER THE DEATH

Were the parents able to stay with their child after the death for as long as they wanted? Were they given the opportunity of holding/washing/dressing their child? Were they given any mementoes, e.g. photographs,hand & foot prints, lock of hair? Did their other child/children have an opportunity of saying good-bye in an unhurried way?

POST- MORTEM AND CORONER

Were the parents satisfied with the attitude and care of the coroner's officer? Were the findings explained clearly?

INFORMATION AND FOLLOW-UP

Were the parents given any leaflets from the hospital? Were they given an appointment to see the doctor at the hospital to talk of the death? Were they given guidelines as to what to do, such as registering the death?

THE FUNERAL

Was the funeral director, priest/vicar helpful? Was the funeral conducted in the way that the parents wanted? If there are other children, did they/will they attend the funeral?

THE MEDIA

Have the Media caused any problems?

OTHER MEMBERS OF THE FAMILY

PARENTS

Are the parents able to talk together about the death? Are they finding that they have different feelings at different times from each other? Are they finding it difficult to be close to each other?

GRANDPARENTS

Are the grandparents able to talk about the death with the parents? Do they have different attitudes to the death? Are the grandparents able to help? Do they need help?

OTHER CHILDREN

Do the other children know about the death? Do the parents have difficulty in talking to them? Are the parents able to cry in front of them?

FRIENDS
Do their friends avoid them? Do the parents feel let down by them?

SCHOOLS (where appropriate)
Do the schools know about the death? Are the parents able to talk to the teachers about the death? Do other parents avoid them?

HEALTH
Do the parents usually have good health? Have appetite sleeping and energy levels been affected? Have either of the parents suffered from depression in the past?

SUPPORT

What support is available from partner, family members, and friends? Do the parents feel that they have sufficient support?

PAST LOSSES

Has there been miscarriage,termination,or still birth in the past? If so, are there still painful memories? Have there been deaths of close family or friends recently? some time ago, or when as a child? Do these deaths still cause pain?

SPIRITUAL

Do they believe in God (or a higher being)? Do they feel angry with God? Do they wonder where their child is now? Would they like to talk to a priest etc.

PRACTICAL PROBLEMS

Are there any pract ca problems wh ch are caus ng d fficulty at the present? Wou d they l ke some he p?

FEARS

Do the parents have any fears at the moment?

OTHER AREAS OF CONCERN

STRENGTHS OF FAMILY

NEEDS OF FAMILY

Priorities of the bereaved family may change over time. A list of the main headings is provided for both the first visit and subsequent visits to help plan your care. The coding is a simple guide to help prioritise the family's needs.

Code 1 is for areas which require immediate attention.

Code 2 is for those areas which are not so urgent.

Code 3 is for those areas which require attention once the other areas have been covered.

First Visit

CARE PLAN

	1	2	3
About the death			
After the death			
Post-Mortem and Coroner			
Information and follow-up			
The Funeral			
The Media			
Relationships:			
Partner			
Siblings			
Grandparents			
Friends			
Schools			
Other parents			
Health			
Support			
Partner			
Family			
Friends			
Past losses			
Spiritual issues			
Practical problems			
Fears			

APPENDIX 3

PHASE 2: LETTERS TO:

STUDY HEALTH VISITORS PRIOR TO START OF STUDY
BEREAVED PARENTS
PARENTS' G.PS
STUDY HEALTH VISITORS WITH QUESTIONNIARE
CONTROL HEALTH VISITORS WITH QUESTIONNAIRE

UNIVERSITY OF BRISTOL

Department of Child Health
Bereavement Project
St. Michael's Hospital
Southwell Street, Bristol BS2 8EG
Telephone: (0117) 928 5356
Fax: (0117) 928 5751

Project Leader — Mrs Ann Dent
P.J. Fleming, MB, ChB, PhD, FRCP, FRCP(C)
Professor of Infant Health and Developmental Physiology

Dear Health Visitor,

Recently we conducted a national study to establish bereaved parents' perceptions of the care they had received since the sudden, unexpected death of their child. (from 1 week to 12 years) The findings showed that bereaved parents found care in hospitals reasonably satisfactory but felt isolated and unsupported in the community. We further found that whilst health visitors and G.Ps considered themselves the most appropriate professionals to support these families, they felt inadequate to do so, due to few policies to guide them and little training.

With a view to improving care where necessary, we are conducting a trial in the South & West region from April 1st 1996 until April 1998, to evaluate interventions designed for health visitors.
I would be grateful if you could use the assessment tool included in the pack when and if you meet a family whose child dies from 1 week to 12 years suddenly and unexpectedly from accident or illness. 3 months from the death, I will send you a questionniare about your care plan and at 6 months from the death will write to bereaved parents asking if they would complete a questionnaire about their care since the death.
Approval has been given by your local ethics committee.
I hope to hear of any relevant death throughout the region, through the already existing CESDI network, and will inform you of any in your district, especially of children who die over the age of 5 years.
The aim of this project is not to give you more work but to offer help in a difficult and sensitive area of your care.

I do hope you will feel able to support this research, which I hope will ultimately help health visitors and bereaved families nationally.

Thanking you in anticipation for your help.

Yours sincerely,

Ann Dent Project Leader.

Dear

Our records in the Dept of Child Health show that very sadly ..... died suddenly last ..... I am so very sorry and can only imagine that the last six months must have been devastating for all concerned. As a former nurse working with children. I am now trying to improve care for families whose children die suddenly and unexpectedly as there is no preparation for such a tragic event and I do believe that families who go through this experience deserve the best of care.

With this in mind, we recently conducted a national study to find out what bereaved parents thought of the help they had received after the sudden death of their child. We found that many parents felt isolated and unsupported.
I am now trying to improve care where needed by helping health visitors especially. I am so sorry to bother you at this time, but what you can tell me is invaluable.
Only you will know what help is best after such a loss.

I would like to send you simple questionnaires which ask about the care you have received from your health visitor over the past 6 months. Your G.P and health visitor know that I am writing to you, but anything you tell me will be in strict confidence.
*If you **would like to help** other parents by helping with the study, **do nothing** and I will send you questionnaires within the next fortnight.
*If you **do not wish to take part,** I would be grateful if you could complete the form at the end of this letter as soon as possible , so that I don't bother you further. A stamped addressed envelope is enclosed for your convenience.
With all good wishes,
Yours sincerely,

.....

Reply to Bereavement Project

I/we do not wish to take part in the study.....

Father's Name.....

Mother's name.....

UNIVERSITY OF BRISTOL

Department of Child Health
Bereavement Project
St. Michael's Hospital
Southwell Street, Bristol BS2 8EG
Telephone: (0117) 928 5356
Fax: (0117) 928 5751

Project Leader — Mrs Ann Dent
P.J. Fleming, MB, ChB, PhD, FRCP, FRCP(C)
Professor of Infant Health and Developmental Physiology

Dear Dr

We recently conducted a study in 7 of the 14 former regions of England and Wales to ascertain:
(a) bereaved parents' perceptions of the care they had received since the sudden and unexpected death of their child (from 1 week to 12 years) from accident or unexpected illness, and (b) what statutory and voluntary agencies had offered or could offer to such families.

The findings showed that whilst hospital care was perceived as good on the whole by bereaved parents, they felt isolated and unsupported in the community. Bereaved parents, general practitioners and health visitors all agreed that G.Ps and health visitors were the most appropriate people to provide care and support after the death of a child. However, many G.Ps and health visitors felt ill-equipped to provide such care, because of lack of training and lack of appropriate guidelines or policies within the health care system (Dent A., Condon L., Blair P., & Fleming P. "A Study of Bereavement Care after a Sudden and Unexpected Death", "Archives of Disease in Childhood", Vol 74, No 6, 1996, 522-526).

With a view to improving care where necessary, a randomised controlled trial is being conducted in all health districts of the South and West region as from April 1st 1 996 for 2 years, to establish the efficacy of interventions for health visitors. These come in the form of a bereavement assessment tool and information booklets for health visitors and bereaved parents. Approval has been given by your L.R.E.C. Your district falls into the study/control group.

At 3 months from a death, a questionnaire is being sent to all relevant health visitors, to establish their care plans. I have just sent a questionnaire to your health visitor asking her how she planned care for the family of who died in last.
At 6 months from a death, bereaved parents will be asked if they would each complete a questionnaire about the care they have received since the death.

We trust that you will feel able to support this study which we hope will benefit bereaved families and give health visitors greater confidence in their ability to provide support to such families.
Should you have any queries about the study or concerns about me approaching the parents, please do not hesitate to contact me.

Yours sincerely

Dear

As from 1st April 1996, a randomised controlled trial is being conducted in the South & West region to evaluate the effectiveness of bereavement packs given to health visitors in the study health districts.
I believe that you have received such a pack. As I explained in my original letter, I am now sending you a questionnaire which asks about care of the family of .....who sadly died in .....last.
I would be very grateful if you could find time to complete it, as this will assist me greatly in assessing how useful the pack is. As you know, the main aim of the study is to empower health visitors to feel more confident in supporting bereaved families so that they feel less isolated. Your help is therefore crucial to the success of this project.

I would also be grateful if you could pass on the enclosed letter to the family G.P. so that (s)he may know of the study. Unless I hear otherwise, I shall be contacting the bereaved parents 6 months from the death, to ask if they would be willing to complete questionnaires.

I would like to stress that any information given by you or the family will be held in the strictest confidence and no health district, family or health visitor will be identifiable.

Thanking you in anticipation for your help.

Yours sincerely,

Dear (Health Visitors),

We recently conducted a national study to assess bereaved parents' perceptions of the care they received after the sudden death of their child (up to 12 years) We found that many parents felt isolated and unsupported and that health visitors and G.Ps felt that they were the most appropriate professionals to support these families, although they felt uncertain and inadequate.

As a result of these findings, you are probably aware that a randomised controlled trial is being conducted in the South & West region, to evaluate the effectiveness of bereavement packs for health visitors working with bereaved families. All health visitors in the study group have been sent packs. So that I can prove their usefulness, it is important that I include health visitors who do not have the packs (controls)
Before the start of the study, I contacted your manager who has given me permission to include any health visitor in your health district who comes in contact with a bereaved family over the next 2 years. I have also had approval from your local ethics committee.

I know that ..... sadly died in .....last. I would be very grateful if you could find the time to complete the enclosed questionnaire which asks how you planned care for the family. I am also enclosing a letter for the family's G.P, explaining the study. At 6 months from the death, unless I hear to the contrary, I will be contacting the parents to ask if they would be willing to complete questionnaires on the care they received since the death of their child. All information given by you and the family will be held in the strictest confidence, and no one health district or person will be identifiable.
The main aim of the study is to empower health visitors to feel more confident about bereavement care, so that families feel less isolated. Your help to achieve this aim is therefore crucial.

Thanking you in anticipation for your help.
Yours sincerely,

APPENDIX 4

PARENTS' QUESTIONNAIRE IN PHASE 2

BEREAVEMENT PROJECT

PARENTS QUESTIONNAIRE

This project is based at
The Department of Child Health, St. Michael's Hospital,
Bristol BS2 8EG.

If you require further information please contact:
Mrs. Ann Dent, Project Leader. Tel: (0117) 928 5356

We have designed the following questions so that we may find out from you whether the support you have received from the health service in the last 6 months has helped you and your family. Your answers will greatly assist us in finding ways to help bereaved families. All information that you give us will be totally confidential and not shared with your G.P or health visitor. Most questions require just a tick, and so completing the questionnaire should not take up too much of your time.

We would be grateful if you and your partner could complete one questionnaire each so that we may know how you both feel about the support given.

Please indicate who is filling in this questionnaire.

Mother .....

Father .....

Partner .....

Other .....
(please specify)

.....

Section A

This section asks about visits from a health visitor.

1. After the death of your child, did a health visitor make any type of contact with you ? (e.g.phoning, visiting, seeing you in surgery)

Yes ☐
No ☐

2. If Yes, how long after the death was this?

.....days .....weeks ..... months

If she made no contact, please go to Section C Question 1.

3 D d you ever have contact with the health visitor before the death?

Yes ☐
No ☐
Don t know ☐

4 f Yes d d prev ous contact with the health visitor make it easier to talk about the death?

Yes ☐
No ☐
Don t know ☐

5 Did you f nd the t m ng of the first visit from the health visitor:

too soon after the death ☐
just r ght ☐
too long after the death ☐
don t know ☐

6. Did your health visitor explain that she was there to support your family in bereavement?

Yes ☐
No ☐
not sure ☐

7. Did the health visitor continue to visit after the first visit?

Yes ☐
No ☐

8. Please could you give us details of **all** contact you have had with your health visitor since the death of your child, including the first visit (e.g.visits, phone calls, seen in GP surgery)?

Type of contact (approx.)	Days since the death (approx.)	Length of this contact (hrs and mins)

9. Since the death, do you think the **number of visits** from your health visitor has been :

just right? ☐
too many? ☐
too few? ☐
don't know ☐

10. Have you found the time **between visits** from your health visitor:

Just right? ☐
too long? ☐
too soon? ☐
don't know ☐

Section B

This section asks about the bereavement care you have received from your health visitor since the death of your child

1. Did your health visitor ask any questions about the following:

	Yes	No	Don't know
your present physical health	☐	☐	☐
your past physical health	☐	☐	☐
your present emotional health	☐	☐	☐
your past emotional health	☐	☐	☐
any deaths you have experienced in the past	☐	☐	☐
any practical difficulties you were having after the death	☐	☐	☐
your spiritual needs (e.g.the meaning of life now, losing or finding a faith)	☐	☐	☐

Relationships

2. Did your health visitor ask about how the following relationships had been before the death?

	Yes	No	Don't know
Your relationship with your partner	☐	☐	☐
Your relationship with your child/children	☐	☐	☐
Your relationship with the grandparents	☐	☐	☐
Your relationships with friends and family	☐	☐	☐

3. Did your health visitor ask if any of the following relationships had changed since the death?

	Yes	No	Don't know
Your present relationship with your partner	☐	☐	☐
Your present relationship with your children (child)if any	☐	☐	☐
Your present relationship with any grandparents	☐	☐	☐
Your present relationship with family and friends	☐	☐	☐

Helping your other children

If you have no other children, please go to Question 6 in this section.

4. Did your health visitor include other children in the family in her care?

Yes ☐ No ☐

5. Did your health visitor give information or guidance on how to help your child or children with their grief?

	Information	Guidance
Yes	☐	☐
No	☐	☐

6. If Yes, how helpful was it?

	Information	Guidance
very helpful	☐	☐
fairly helpful	☐	☐
not at all helpful	☐	☐
don't know	☐	☐

About Grandparents

If there are no grandparents please go to Question 8 in this section.

6. If there are grandparents, did your health visitor include them in her care?

Yes ☐
No ☐
Not applicable ☐

7. If yes, how did she help?
(please tick appropriate boxes)

Talked to them personally ☐
Gave you advice to pass to them ☐
Gave them information ☐
Gave you information to pass to them ☐
Other (please state) ☐

8. Is there anyone else in your close family who was given care by the health visitor?
(please state whom)

9. Is there anyone else in your family whom you feel should have been offered help but wasn't?

Yes ☐
No ☐
Don't know ☐

10. If yes, who was this?

Information

11. Did your health visitor give you any information about what to expect in bereavement?

Yes ☐
No ☐

12. If yes, what information did she give you?

13. Did you find this information

very helpful? ☐
fairly helpful? ☐
not at all helpful? ☐

14. Is your health visitor still visiting you?
(please tick the box which is most appropriate)

Yes, and I find it useful ☐
Yes, but I don't find it useful ☐
No, but I would welcome it ☐
No, but I wouldn't want her to ☐
No, but I don't need her help now ☐

15. Can you contact her if you need her?

Yes ☐
No ☐
Don't know ☐

16. Every bereaved family is unique. Did your health visitor involve you in planning the care that was right for your family?

Yes ☐
No ☐
Dont' know ☐

17. Have you found your health visitor:

very supportive ☐
fairly supportive ☐
not at all supportive ☐

18. Have you found your health visitor:

very caring ☐
fairly caring ☐
not at all caring ☐

Section C

This section asks about the overall support you have received since the death of your child.

1. Whom do you think are appropriate professionals to support families after the death of a child? (You may tick up to four).

	Yes	No	Don't know
G.P	☐	☐	☐
Health visitor	☐	☐	☐
Social Worker	☐	☐	☐
Bereavement Counsellor	☐	☐	☐
Member of the clergy	☐	☐	☐
Hospital Doctor	☐	☐	☐
Hospital Nurse	☐	☐	☐
Don't know	☐	☐	☐

Other (please state) .....

2. From whom have you received bereavement support over the past 6 months? (please tick as many as are appropriate)

Partner	☐
Family	☐
Friends	☐
Church	☐
G.P	☐
Health visitor	☐
Support group	☐
Helpers from Bereavement Agency	☐
No-one	☐

Other (please state) .....

3. Have you found the support you have received in the last six months to be satisfactory for you?

Very satisfactory ☐
fairly satisfactory ☐
not at all satisfactory ☐

4. What other help if any, would you have liked over the past 6 months? (Please tick as many as appropriate)

More visits from G.P ☐
More visits from health visitor ☐
More information about bereavement ☐
Help from a bereavement counsellor ☐
Being part of a Support group ☐

Other (please state) .....

About your children

If you have no other children please go on to Section D Question 1.

5. If you have other children, what are their ages?

Name	Age	Male	Female

6. Have you noticed any changes in their behaviour since the death?

Yes ☐
No ☐
Don't know ☐

7. If Yes, what changes in behaviour have you noticed?

Becoming withdrawn	☐	Telling fibs	☐
Unable to concentrate	☐	Aggressive behaviour	☐
Bedwetting	☐	Stealing	☐
Being bullied	☐	Other	☐
Bullying others	☐	(Please describe)	

8. Have you asked for any professional help for your children other than from the health visitor?

Yes ☐
No ☐

If yes, please state who this was:

9. Would you have liked further information or guidance on bereavement care of your children?

	Information	Guidance
Yes	☐	☐
No	☐	☐
Don't know	☐	☐

Section D

This section asks about your health since the death.

1. Approximately how many days did you feel ill in the year **before** the death?

   .....days

2. In the year **before** the death, how many times did you see your G.P because of illness?

   not at all ☐
   once ☐
   2-3 times ☐
   4-6 times ☐
   more than 6 times ☐

3. If you are employed, approximately how many days sickness did you have in the year before the death?

   .....days

4. **Since your child died**, approximately how many days have you felt unwell?

   ..... days

5. **Since the death**, how often have you visited your G.P.?

   not at all ☐
   once ☐
   2-3 times ☐
   4-6 times ☐
   more than 6 times ☐

6. If you are employed, approximately how many days sickness have you had since the death?

..... days

7. As a result of the death, have you seen any of the following professionals? (please tick as many boxes as appropriate)

Psychologist	☐
Psychiatrist	☐
Social Worker	☐
Bereavement Counsellor (in the hospital)	☐
Other involved in the health service (please state)	☐

.....

8. As a result of the death, have any of your close family seen any of the following professionals?

	Partner	Children	Grand-parents	Other (specify)
Psychologist	☐	☐	☐	.....
Psychiatrist	☐	☐	☐	.....
Social Worker	☐	☐	☐	.....
Bereavement Counsellor (in the hospital)	☐	☐	☐	.....
Other involved in the health service (please state)	☐	☐	☐	.....

.....

9. **In the past week**, have you experienced any of the following?:

	Yes	No	Don't know
I have worried about every little thing.	☐	☐	☐
I have been breathless or had a pounding of my heart.	☐	☐	☐
I have been so worked up that I couldn't keep still.	☐	☐	☐
For no good reason, I have had feelings of panic.	☐	☐	☐
I have had a pain or tense feeling in my neck or head.	☐	☐	☐
Worrying has kept me awake at night.	☐	☐	☐
I have been so anxious that I couldn't make up my mind about the simplest thing.	☐	☐	☐

10. In the same way, have you experienced any of the following **in the last week?:**

	Yes	No	Don't know
I have been so miserable that I have had difficulty sleeping.	☐	☐	☐
I have been depressed without knowing why.	☐	☐	☐
I have gone to bed not caring if I never woke up.	☐	☐	☐
I have been so low in spirit that I have sat for ages doing absolutely nothing.	☐	☐	☐
The future seems hopeless.	☐	☐	☐
I have lost interest in just about everything.	☐	☐	☐
I have been so depressed that I have thought of doing away with myself.	☐	☐	☐

Section E

We ask the final questions to find out what care is given to different families in different parts of the South & West region.

1. How old were you on your last birthday? .....years

2. What is your present marital status?

Married	☐
living with partner	☐
supported by partner but not living together	☐
Single	☐
Widowed	☐
Separated	☐
Divorced	☐
Other (please state)	☐

3 What is your usual occupation? (Please give as much detail as possible)

4. Are you currently employed?

Yes	☐
No	☐

5. Which of the following best describes your ethnic group?

White	☐		
Black-Caribbean	☐	Black-African	☐
Black-other	☐	Indian	☐
Pakistan	☐	Bangladeshi	☐
Chinese	☐	Other (please describe)	☐

Please feel free to add any comments about the death of your child, or the care you have received since the death.

Thank you so much for your time and help.

APPENDIX 5

HEALTH VISITORS' QUESTIONNAIRE IN PHASE 2

No.....

BEREAVEMENT PROJECT

QUESTIONNAIRE FOR HEALTH VISITORS

This project is based at:

The Department of Child Health, St Michael's Hospital, Bristol BS2 8EG

For further information please contact Mrs Ann Dent - Tel. 0117 9285356

NB "Child" will be used as the generic term for babies aged 1 week to 12 years

Section A

This section asks general questions about yourself and bereavement care in your health district.

1. How long have you been qualified as a health visitor?

   .....years .....months

2. How long have you practised as a health visitor?

   .....years .....months

3. Since you qualified as a health visitor, how many times (including this recent one) have you been involved professionally with a family after the sudden, unexpected death of a child?

Age of child	Cause of death	How long ago years..... months.....

4. In your health district, is there a policy on how to care for a family after the sudden and unexpected death of a child?

   Yes ☐
   No ☐
   Don't know ☐

5. If there is a policy, has this helped you in caring for your recent bereaved family?

   Yes ☐
   No ☐
   Don't know ☐

6. Have you undertaken any training in the following:

a) General bereavement care ?

Yes ☐
No ☐

b) Sudden, unexpected death of a child?

Yes ☐
No ☐

If **No** to both questions please go straight to Question 10.

7. If Yes, of what did this training consist?

	Bereavement Training	Sudden death of a child
half a day	☐	☐
several days	☐	☐
1 week	☐	☐
2 weeks	☐	☐
more than 2 weeks	☐	☐
Other (please state)	☐	☐

8. Did you think, before meeting the recent family, that this training had met your needs for supporting a bereaved family?

	Bereavement Training	Sudden death of a child
Yes, partly	☐	☐
Yes, completely	☐	☐
No	☐	☐
Don't know	☐	☐

9. If No, what training/information would you have liked?

	Training	Information
Bereavement		
Sudden death of a child		

10. Whom do you think are appropriate professionals to support a family after the sudden and unexpected death of a child? (You may tick more than one)

G.P.	☐
Health visitor	☐
Social worker	☐
Bereavement counsellor	☐
Member of the clergy	☐
Hospital Doctor	☐
Hospital nurse	☐
Other	☐

11. Whom do you think is the **most** appropriate professional to support a family after the sudden, unexpected death of a child? Please give reasons.

12. Do you think health visitors have a significant role in supporting a family whose child has died suddenly and unexpectedly? Please give reasons.

Section B

This section asks questions on how you felt prior to visiting your recent bereaved family.

1. When you first heard that you had a family on your case-load whose child had died suddenly and unexpectedly, how did you feel before visiting?

   very anxious ☐
   moderately anxious ☐
   not at all anxious ☐

2. If you were at all anxious, why was this?

3. Before visiting, how confident did you feel about supporting the bereaved family?

   very confident ☐
   moderately confident ☐
   not at all confident ☐
   not sure ☐

4. Did you have contact with the bereaved family before the death?

   Yes, and had contact many times ☐
   Yes, and had contact a few times ☐
   Yes, and had contact once ☐
   No ☐
   Not sure whether I have had contact ☐

5. If Yes, do you think this

- helped a lot? ☐
- helped a little? ☐
- didn't help at all ☐
- made no difference? ☐
- don't know ☐

Section C

This section asks about your contacts with the bereaved family and how you planned future care.

1. Please write down all contact you have had with the family since the death (e.g. visiting, seen in surgery, by phone):

Type of Contact	No of days since death (approximately)	Length of contact (approximately)

2. Did you decide to continue visiting after the first visit?

Yes ☐

No ☐

3. If No, please give reasons for not continuing to visit.

4. If you decided to continue visiting, how did you decide on how often this should be?

5. After the first visit to the family, did you feel

not at all anxious? ☐

less anxious than before? ☐

just as anxious? ☐

more anxious than before? ☐

6. In planning care for the family, did you ask about any of the following:

	Yes	No	Not sure
Present physical health	☐	☐	☐
Past physical health	☐	☐	☐
Present psychological health	☐	☐	☐
Past psychological health	☐	☐	☐
Past significant losses/deaths	☐	☐	☐
Spiritual issues (as opposed to religious)	☐	☐	☐
Present practical difficulties	☐	☐	☐
Socio-cultural issues	☐	☐	☐

7. In planning care did you ask whether any of the following relationships had changed **since** the death?

	Yes	No	Not sure
Relationship of partners	☐	☐	☐
Parents and grandparents	☐	☐	☐
Parents and siblings (if any)	☐	☐	☐
Attitude and reactions of friends and other family members	☐	☐	☐

8. When visiting the bereaved family, did you have contact with:

	Yes	No	Don't know	N/A
mother?	☐	☐	☐	☐
partner?	☐	☐	☐	☐
father?	☐	☐	☐	☐
siblings?	☐	☐	☐	☐
grandparents?	☐	☐	☐	☐
other members of family? (please state)	☐	☐	☐	☐

9. What help were you able to offer the siblings (if there were any):

10. Are you still visiting the bereaved family?

Yes ☐
No ☐

11. If you have stopped visiting, what were your reasons?

12. Is the Neuman's systems model used in your health district for general assessment of families' needs?

Yes ☐
No ☐
Don't know ☐
Haven't heard of Neuman's Systems model ☐

13. If yes to the above, do you think this has helped you in planning care for the bereaved family?

Yes ☐
No ☐
Don't know ☐

Section D

This section asks about referrals.

1. Has the family been referred to any of the following?

A voluntary agency?	☐
Psychiatrist?	☐
Psychologist?	☐
Social worker?	☐
Other? (please state)	☐

2. Was this referral made at your request?

Yes	☐
No	☐

3. If yes, for what reason?

Section E

This section asks how you feel about the care you have given.

1. How effective do you consider the care you have given to the bereaved family over the last 2 months?

very effective	☐
effective	☐
fairly effective	☐
ineffective	☐
very ineffective	☐
don't know	☐

2. If you rated the care as very effective, effective, or fairly effective, why do you think this was?

3. If you rated the care as ineffective, very ineffective, or you don't know, why do you think this was?

Section F

This section asks about the support you have had.

1. When supporting the bereaved family, from whom have you received support?

Colleagues	☐
Family	☐
Friends	☐
Support Group	☐
Counsellor	☐
None	☐
Other (Please state)	☐

2. Do you think this support has been adequate?

Yes	☐
No	☐
Not sure	☐

3. If it was not, what support would you have liked?

Section G

This section asks questions about the Information Pack and Bereavement Assessment Tool. Questions are asked about each separately.

ASSESSMENT TOOL

1. Overall, have you found the bereavement assessment tool:

   very helpful? ☐
   quite helpful? ☐
   not at all helpful? ☐

2. Did you find that it was:

   too short? ☐
   just right? ☐
   too long? ☐

3. Did you find the format easy to use?

   Yes ☐
   No ☐
   not sure ☐

4. Did the "guidelines for health visitors" assist you in using the assessment tool?

   Yes ☐
   No ☐
   Don't know ☐

5. Do you think the assessment tool helped you to plan better care for bereaved parents and their families?

   Yes ☐
   No ☐
   Don't know ☐

6. When supporting the bereaved family did you find that the assessment tool:

increased your anxiety? ☐

didn't make any difference to your anxiety? ☐

reduced your anxiety? ☐

7. Did you find that having the assessment tool, influenced you in continuing to visit the bereaved family?

Yes ☐

No ☐

Don't know ☐

8. Do you think the assessment tool gave you more confidence to work with families?

Yes ☐

No ☐

Don't know ☐

9. Did the assessment tool give you a better understanding of bereavement?

Yes ☐

No ☐

don't know ☐

Please add any comments you have on the assessment tool:

Section H

INFORMATION PACK

1. Did you find the information booklet on "guidelines for health visitors":

   useful? ☐
   quite useful? ☐
   not at all useful? ☐

2. Was the booklet

   too long? ☐
   just right? ☐
   too short? ☐

3. What (if any) other information would you like for yourself?

4. Did the parents find the booklet "Guidelines for bereaved parents":

   Helpful? ☐
   quite helpful? ☐
   not at all helpful? ☐
   Don't know? ☐

5. What other information do you think would be useful for bereaved parents?

Please add any other comments about the information pack

6. Do you think it would be helpful for all health visitors to have access to:

	Yes	No	Don't know
an assessment tool?	☐	☐	☐
an information pack?	☐	☐	☐

It would be very helpful if you could add any comments you may have about:

a) The Bereavement Care of the family

b) Bereavement Care generally

c) This Questionnaire

Thank you so much for your help and time

APPENDIX 6

REMINDERS TO: *PARENTS AND HEALTH VISITORS*

Dear

I am so sorry to bother you again. I recently sent you a letter asking if you would be willing to complete questionnaires on the care you have received since the death of . It would appear from my records that we have not heard from you.

I would be very grateful if you could let me know whether you would like to receive questionnaires, one for each of you , which are very simple and should not take up too much of your time. Your comments would be much valued, so that we know how parents and families are being cared for and , where necessary, can ensure that care is improved.

I look forward to hearing from you.

Yours sincerely,

Ann Dent- Project Leader

Dear (Health Visitor),

I am so sorry to bother you again. I recently sent you a questionnaire asking about how you planned care for the family of ..... From my records it would appear that as yet it has not been returned.

As the information you give is so vital to this project which ultimately I hope will help health visitors and bereaved families, I would be very grateful if you could find the time to complete it and return it to me as soon as you are able

I look forward to hearing from you. If you have already returned the questionnaire, recently please ignore this letter.

Yours sincerely,

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